



Department of Psychology  
& Speech Pathology

# Interpersonal and Organisational Development Research Group

IOD Occasional Papers: Number 2/00

**Support Network on Disability: A resource  
guide to disability groups and organisations**

*Manuel Aramayo*



**Support Network on Disability: A resource guide to disability groups  
and organisations**

**Manuel Aramayo**

Universidad Central de Venezuela and Interpersonal *and* Organisational Development  
Research Group, Manchester Metropolitan University

*This directory was compiled whilst Manuel Aramayo was on study leave at  
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**MISSION:**

To undertake research and consultancy which informs policy, enhances the effectiveness of organisations, and enhances the lives of vulnerable people by asking meaningful questions, encouraging the participation of those involved in the research and disseminating the findings to all those with a stake in the research

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# **SUPPORT NETWORK ON DISABILITY**

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## Preface

Professionals working in the field of Disability often need to be able to contact different kinds of organizations. Sometimes we need to find a particular book, article, paper or reference. As practitioners working with people directly, particularly with parents we may need to refer somebody to a particular association, or group of parents, so that they can get information, advice or personal support for the care of their child with special needs. This aim of this Directory is to provide an immediate contact, telephone or e-mail for groups and organizations, mainly in the UK and Spain.

All the addressees have been taken from recent sources. However, it may still be that an address or telephone number will have changed. In this case, up to date information may be available from one of the more general organizations or federations, such as, for example, the CaF Directory or a national Down's Syndrome Association.

Whilst the Directory includes a wide range of organizations and parents' groups, there will be some that have been omitted. I do apologize for not including other valuable references. I have included sections on Downs syndrome and attention deficit hyperactivity disorder, as these are my particular professional interests. The UK and Spain are the main European countries of reference, although I have included some international agencies in Europe and some in the United States of America. A new work – Volume II- will be dedicated to creating a Support Network Directory for Venezuela and Latin America. We urgently need resources that will help us to organize, and to be in regular contact and exchange with families, professionals and organizations from all over the world with a common interest: working in ways to benefit disabled people with those with special needs.

This work is one outcome, amongst others, of my six months postdoctoral study programme at the Manchester Metropolitan University. I am grateful to the Universidad Central de Venezuela as well as to the Manchester Metropolitan University for enabling me to have a productive and stimulating postdoctoral study programme.

I hope you find the Directory of use, and would welcome any comments, or suggestions for additions or amendments to the directory.

Manual Aramayo,  
April, 2000, Manchester, UK.

If you would like an electronic version of this report please contact [C.Kagan@mmu.ac.uk](mailto:C.Kagan@mmu.ac.uk)

## **UNITED KINGDOM**

### ***DISABILITY ASSOCIATIONS, UNIVERSITIES, SERVICES AND SUPPORT GROUPS***

#### **INDEPENDENT GROUPS AND PUBLIC SERVICES**

##### **ACCESS COMMITTEE FOR ENGLAND**

12 City Forum  
250 City Road  
LONDON EC1V 8AF  
Tel: 020 7250 0008  
Fax: 020 7250 0212  
Minicom: 020 7250 4119

##### **ADVISORY CENTRE FOR EDUCATION**

ACE  
1b Aberdeen Studios  
22 Highbury Grove  
London N5 2DQ  
Tel: 020 73548321  
Fax: 020 7354 9069  
[www.ace.-edorg.uk](http://www.ace.-edorg.uk)

##### **BENEFIT ENQUIRY LINE**

Disability Benefits Including  
Disability Working Allowance  
(Better off advice)  
Tel: 0800 882200

##### **BOLTON INSTITUTE**

A National Centre Promoting Inclusive Education  
Chadwick Street  
Bolton BL2 1JW  
Tel: (01204) 528851 / 900600  
Fax: (01204) 399074  
Joe Whittaker  
[j.whittaker@bolton.ac.uk](mailto:j.whittaker@bolton.ac.uk)

##### **BRITISH COUNCIL FOR DISABLED PEOPLE**

BCDP  
Litchurch Plaza  
Litchurch Lne  
Derby DE24 8AA  
Tel: 01332 295551  
Fax: 01332 295580  
[www.bcodp.org.uk](http://www.bcodp.org.uk)

##### **BRITISH INSTITUTE FOR LEARNING DISABILITIES**

Wolverhampton Road  
Kidderminster  
Worcs DY10 3PP  
Tel: 01562 850251  
Fax: 01562 851970  
[www.bild.org](http://www.bild.org)  
[bild@bild.demon.co.uk](mailto:bild@bild.demon.co.uk)

**BURY PARENT PARTNERSHIP**

Hurdless Day Centre,  
Herbert Coates Community Centre,  
Morley Street, Bury  
BL9 9JQ  
Tel: 0161 797 0082  
Helpline: 0161 763 5001

**BUSINESS LINK**

Business Link FREEPOST  
Lon 13319  
London EC4B 4HF  
Tel: 0345 567765  
Fax: 020 7557 7301

**CARERS NATIONAL ASSOCIATION**

20-25 Glasshouse Yard  
London EC1A 4IS  
Tel: 020 7490 8898

**CENTRE FOR ACCESSIBLE ENVIRONMENTS**

Nutmeg House  
60 Gainsford Street  
London SE1 2NY  
Tel: 020 7357 8182  
Fax: 020 7357 8183

**COALITION FOR DISABLED PEOPLE -MANCHESTER**

Carlsbrook  
Wenlock Way, Gorton  
Manchester M12 5LF  
Tel: 0161 273 5154  
0161 273 5155

**CONTACT A FAMILY**

CaF  
170 Tottenham Court Road  
London W1P 0AH  
Tel.: 020 783 3555  
Fax: 020 783 0259  
[www.cafamily.org.uk](http://www.cafamily.org.uk)

**COUNCIL FOR DISABLED CHILDREN**

National Children's Bureau  
8 Wakley Street  
London EC1 7QE  
Tel: 020 7843 6000  
Fax: 020 7278 9512  
[www.ncb.org.uk](http://www.ncb.org.uk)



CROSSROADS  
Respite care  
10 Regent's Place  
Rugby  
Warks CV21 2PN  
Tel: 01788 573653  
Fax: 91788 565498

CRUSE  
(Bereavement support)  
Cruse House  
126 Sheen Road  
Richmond  
Surrey TW9 1UR  
Tel: 020 8940 4818  
Fax: 020 8940 7638

CSIE-CENTRE FOR STUDIES ON INCLUSIVE EDUCATION  
1 Redland Close - Elm Lane  
Redland. Bristol BS6 6UE  
Tel: 0117 923 8450. Fax: 0117 923 8460  
<http://inclusion.uwe.ac.uk>

DAYCARE TRUST  
Shoreditch Town Hall Avenue  
380 Old Street  
London EC1V 9LT  
Tel: 020 7739 2866  
Fax: 020 7739 5579  
[www.daycaretrust.org.uk](http://www.daycaretrust.org.uk)

DIAL UK  
Par Lodge  
St Catherine's Hospital  
Tickhill Road  
Doncaster DN4 8QN  
Tel: 01302 310123  
Fax: 01302 310404  
[dialuk@aol.com](mailto:dialuk@aol.com)

DISABILITY ACCESS RIGHTS ADVICE SERVICE  
DARAS  
(Queries about Disability Discrimination Act from groups (including parents groups)  
not individuals  
The Chandlery  
50 Westminster Bridge Road  
London SE1 7QY  
Tel: 0345 585445  
Fax: 0345 585446  
[www.daras.co.uk](http://www.daras.co.uk)

DISABILITY ALLIANCE  
Benefit advice  
Universal House  
88-94 Wentworth Street  
London E1 7SA  
Tel: 020 7247 8763

DISABLED LIVING FOUNDATION

DLF

380-384 Harrow Road

London W9 2HU

Tel: 020 7289 6111 (Admin)

Fax: 020 7266 2922

Helpline: 870 603 9177

Minicom: 0870 603 9176

[www.dlf.org.uk](http://www.dlf.org.uk)

[dlfinfo@dlf.org.uk](mailto:dlfinfo@dlf.org.uk)

EQUAL OPPORTUNITIES COMMISSION

Overseas House

Quay Street

Manchester M3 3HN

Tel: 0161 833 9244

Fax: 0161 835 1657

[www.eoc.org.uk](http://www.eoc.org.uk)

FAMILY FUND

Grants and information related to the care of very severely disabled children

PO Box 50

York

Yorks YO1 9ZX

Tel: 01904 658085

Fax: 01904 652625

[www.familyfundtrust.org.uk](http://www.familyfundtrust.org.uk)

FEDERATION OF LOCAL SUPPORTED LIVING GROUPS

John Tiernan House

Community Enterprise Centre

90 - 102, Ribble Road

Platt Bridge, Wigan

WN2 5EL

Tel: 01942 516005

(Kath McKinstry;

Sheila Morris

[KSMorris@typical.u-net.com](mailto:KSMorris@typical.u-net.com)

FRIENDS FOR YOUNG DEAF PEOPLE

FYD

East Court Mansion

College Lane

East Grinstead

West Sussex RH19 3LT

Tel: 01342 300080

Fax: 01342 410232

Minicom: 01342 324164

GINGERBREAD

For lone parents

16-17 Clerkenwell Close

London EC1R 0AA

Tel: 020 73368183 Fax: 020 7336 8185

[www.gingerbread.org.uk](http://www.gingerbread.org.uk)

#### HAPA

Adventure playgrounds for children with disabilities  
Pryors Bank  
Bishops Park  
London SW6 3LA  
Tel: 020 7731 1435  
Fax: 020 77314426

#### INDEPENDENT LIVING FUND 1993

P.O. box 183  
Nottingham NG8 3RD  
Tel: 0115 942 8191 - 0115 942 8192  
Fax 0115 929 3156  
[/S=ind.living.fund.hq/@lyt008.dss.gov.uk](mailto:/S=ind.living.fund.hq/@lyt008.dss.gov.uk)

#### INDEPENDENT PANEL FOR SPECIAL EDUCATION ADVICE

##### IPSEA

22 Warren Hill Road  
Woodbridge  
Suffolk IP12 4DU  
Tel: 0394 382814  
Fax: 01394 382814

(Source of independent advice and expert second opinion for parents of children who come within the scope of the Education Act 1993).

#### KIDS' CLUBS NETWORK

Out of school clubs  
Bellerive House  
3 Muirfield Crescent  
London E14 9SZ  
Tel: 020 7512 2112  
Fax: 020 7512 2010  
[www.kidsclub.com](http://www.kidsclub.com)

#### MANCHESTER SOCIAL SERVICES

Joint Learning Disability Service- Social Services Office  
102 Manchester Rd. Chorlton cum Hardy  
Manchester M21 9SZ  
Tel: 0161 881 0911  
Fax: 0161 881 0051

Mark Burton

Head of Development and Clinical Services  
[mark.burton@mcr1.poptel.org.uk](mailto:mark.burton@mcr1.poptel.org.uk)

#### MENCAP -MANCHESTER-

Central and South Manchester MENCAP  
Crossacres Resource Centre  
1 Peel Hall Road  
Wythenshawe  
Manchester M22 5DG  
(Judd Skelton)  
Tel: 0161 437 9455

#### MENCAP NATIONAL CENTRE

123 Golden Lane  
London EC1Y 0RT  
Tel: 020 7454 0454  
Fax: 020 7608 3254

MOTABILITY  
Goodman House  
Station Approach  
Harlow  
Essex CM20 2ET  
Tel: 01279 635666  
[www.motability.co.uk](http://www.motability.co.uk)

NATIONAL ASSOCIATION OF VOLUNTEER BUREAUX  
16 Waterloo Street  
Birmingham B2 5UG  
Tel: 0121 633 4555  
Fax: 0121 633 4043

NATIONAL CHILDMINDING ASSOCIATION  
NCMA  
8 Mason's Hill  
Bromley  
Kent BR2 9EY  
Tel: 020 8464 6164  
Fax: 020 8290 6834

NATIONAL COUNCIL FOR ONE PARENT FAMILIES  
255 Kentish Town Road  
London NW5 2LX  
Tel: 020 7267 1361  
Fax: 020 7482 4851

NATIONAL DEVELOPMENT TEAM  
St Peter's Court. 8 Trumpet Street  
Manchester M1 5LW. Tel: 0161 228 7055  
Fax: 0161 228 7059  
[www.ndt.org.uk](http://www.ndt.org.uk)  
[Office@ndt.org.uk](mailto:Office@ndt.org.uk)

NATIONAL DISABILITY COUNCIL  
Information on Disability Discrimination Act  
Level 4a Caxton House  
Todhill Street  
London SW1H 9DA  
Tel: 0345 622633  
Fax: 0345 622611  
[www.disability.gov.uk](http://www.disability.gov.uk)

NATIONAL NETWORK OF PARENTS PARTNERSHIP SCHEMES  
(Special educational needs support  
c/o Council for Disabled Children)  
National Children's Bureau  
8 Wakley Street  
London EC1 7QE  
Tel: 020 7843 6000  
Fax: 020 7278 9512  
[www.ncb.uk](http://www.ncb.uk)

NATIONAL SOCIETY FOR PREVENTION OF CRUELTY TO CHILDREN  
NSPCC  
42 Curtain Road  
London EC2A 3NH  
Tel: 020 7825 2500  
Fax: 020 7825 2525  
[www.nspcc.org.uk](http://www.nspcc.org.uk)

NATIONAL TOY LIBRARIES ASSOCIATION  
68 Churchway  
London NW1 1LT  
Tel: 020 7287 9592

NETWORK '81  
(Support for parents whose children are statemented)  
1-7 Woodfields Terrace  
Stansted  
Essex CM24 8AJ  
Tel: 01279 647415

NEW WAYS TO WORK  
(Flexible working advice)  
22-25 Northumberland Avenue  
London WC2N 5AP  
Tel: 020 7930 3355  
Fax: 020 7930 3366

NIGEL CLARE NETWORK TRUST  
NCNT  
(Career support for parents of children with life-threatening conditions)  
85 Moorgate  
London EC2M 6SA  
Tel: 020 7256 8313  
Fax: 020 7638 8648  
[www.nigelclare.org](http://www.nigelclare.org)

ORDINARY LIFESTYLES  
Victoria Mill, Lower Vickers Street (off Varley St)  
Miles Platting  
Manchester M40 7LL  
Tel: 0161 202 0050  
(Kathy Davies; Sheila Morris)

PARENTS AT WORK  
45 Beech Street  
London EC2Y 8AD  
Tel: 020 7628 3565  
Fax: 020 7628 3591

PARENTS FOR INCLUSION  
Unit 2, 70n Lambeth Road  
London SW8 1RL  
Tel: 0207 582 5008/0207 735 7735  
Fax: 0207 735 3828

**PARENT LINK -PARENT NETWORK**

44-46 Caversham Road  
London NW5 2DS  
Tel: 0207 735 1214  
Fax: 0207 735 4692

**PATIENTS ASSOCIATION**

P.O. Box 935  
Harrow  
Middlesex HA1 3YJ  
Tel: 020 8423 9111  
Helpline: 020 8423 8999  
Fax: 020 8981 6719

**PEOPLE FIRST**

207-215 Kings Cross Road  
London WC1X 9DB  
Tel: 0171 713 6400  
Fax 0171 833 1880

**PHYSICALLY DISABLED AND ABLEBODIED**

**PHAB**

(Activities for young people)

Phab England  
Summit House  
50 Wandle Road  
Croydon CR0 1DF  
Tel: 020 8667 9443  
Fax: 020 8681 1399  
<http://web.ukonline.co.uk/phab>

**PLANET**

(Information about toys for children with disabilities)

Cambridge House  
Cambridge Grove  
London W6 0LE  
Tel: 020 874119  
Fax: 020 8741 4505  
<http://www.oneworld.org/scf/planet>

**PRINCESS ROYAL TRUST FOR CARERS**

(Run carers centres)

142 Minories  
London EC3N 1LB  
Tel: 020 7480 7788  
Fax: 020 7481 4729

**PRINCE'S TRUST**

(Support for young people starting up a business)

18 Park Square East  
London NW1 4LH  
Tel: 020 7543 1234  
Fax: 020 7543 1200  
<http://www.princes-trust.org.uk>

PROFESSIONAL ASSOCIATION FOR NURSERY NURSES

PANN

2t James Court

Friar Gate

Derby DE1 1BT

Tel: 01332 343029

Fax: 01332 290310

[www.pat.org.uk](http://www.pat.org.uk)

RIDING FOR THE DISABLED ASSOCIATION

Lavinia Norfolk House

Avenue R

National Agricultural Centre

Stoneleigh Park

Warwickshire CV8 2LY

Tel: 01203 696510

Fax: 0123 696532

ROYAL ASSOCIATION FOR DISABILITY AND REHABILITATION

RADAR

12 City Forum

250 Forum Road

London EC1V 8AF

Tel: 020 7250 3222

Fax: 020 7250 0212

Minicom: 020 7250 4119

ROYAL NATIONAL INSTITUTE FOR THE BLIND

224 Great Portland Street

London W1N 6AA

Tel: 020 7388 1266

Fax: 020 7388 3160

ROYAL NATIONAL INSTITUTE FOR DEAF PEOPLE

RNID

19-23 Featherstone Street

London EC1Y 8SL

Tel: 0808 808 0123

Fax: 0171 296 8199

Helpline Text: 0808 808 9000

Freepost WC1252

London EC1B 1QJ

(RNID publishes "One in Seven")

SCOPE LEISURE RESOURCE CENTRE

17 Clews Road

Oakenshaw

Redditch

Worcestershire B98 7ST

Tel: 01527 404808

Fax: 01527 404808

SKILL NATIONAL BUREAU OF STUDENTS WITH DISABILITIES

336 Brixton Road

London SW9 7AA

Tel 0171 873 9090

WHIZZKIDZ  
1 Warwick Road  
London SW1E 5ER  
Tel: 020 7233 6600  
Fax: 020 7233 6611  
[www.whiz-kidz.org.uk](http://www.whiz-kidz.org.uk)

WOMEN RETURNERS NETWORK  
100 Park Village East  
London NW1 3SR  
Tel: 020 7468 2290



## UNIVERSITIES

### UNIVERSITIES AND COLLEGES CENTRAL ADMISSIONS SERVICE

UCAS

Applying for higher education

Reshill

New Barn Lane

Cheltenham

Glos GL52 3LZ

Tel: 01242 227788

Fax: 01242 544960

[www.ucas.ac.uk](http://www.ucas.ac.uk)

### THE MANCHESTER METROPOLITAN UNIVERSITY

Faculty of Community Studies, Law and Education

Department of Psychology and Speech Pathology

Elizabeth Gaskell Campus

Hathersage Road

Manchester M13 0JA

Tel: 0161 247 2563

Fax: 0161 247 6482

[C.kagan@mmu.ac.uk](mailto:C.kagan@mmu.ac.uk)

### ACCESS SUMMIT

Ground Floor

St Peter's House

Precinct Centre

Oxford Road

Manchester M13 9GH

Tel: 0161 272 7847

Minicom: 0161 273 7307

Fax: 0161 272 7001

[access.summit@umist.ac.uk](mailto:access.summit@umist.ac.uk)

Ann Barlow

Learning Support Co-ordinator

The Manchester Metropolitan University

All Saints

Manchester M15 6BH

Tel: 0161 247 3492

Facsimile: 0161 247 6852

[h.a.barlow@mmu.ac.uk](mailto:h.a.barlow@mmu.ac.uk)

### EQUALITIES OFFICE

University of Salford

Allerton Building Concourse

Frederick Road

Salford M6 6PU

Tel: 0161 295 2152

### OPEN UNIVERSITY

P.O.Box 625

Milton Keynes MK7 6AA

Tel: 0870 9000301 Hotline

[www.open.ac.uk/](http://www.open.ac.uk/)

WORKABLE

St. Peter's House  
Precinct Centre  
Oxford Road  
Manchester M13 9GH  
Tel: 0161 272 7800

CALIM

(Consortium of Academic Libraries in Manchester)  
Manchester Metropolitan University  
Minshull House  
47-49 Chorlton Street Manchester M1 3EU  
Tel: 0161 247 6673  
Fax: 0161 247 6846  
<http://rylibweb.man.ac.uk/calim/>

Michael J. Oliver

Professor of Disability Studies- School of Social Sciences  
The University of Greenwich  
Avery Hill Campus  
Bronte Hall, Southwood Site  
Avery Hill Road, Eltham  
London SE9 2UG  
Tel: 44 020 8331 9588  
Fax: 44(0)20-8331 8905  
[M.J.Oliver@greenwich.ac.uk](mailto:M.J.Oliver@greenwich.ac.uk)

UNIVERSITY OF LEEDS, DISABILITY PRESS

Disability Research Unit,  
Department of Sociology and Social Policy  
Leeds LS2 9JT  
Tel: 0113 243 1751  
[c.barnes@leeds.ac.uk](mailto:c.barnes@leeds.ac.uk)

UNIVERSITY OF KEELE

Dr. J.R. Hegarty  
Computer Applications to Special Education (C.A.S.E.)  
Applied Research Unit  
Psychology Department, Keele University  
Keele, Staffordshire, ST5 5BG  
Tel: 01782 583386  
Fax: 01782 583387  
[psa02@keele.ac.uk](mailto:psa02@keele.ac.uk)

UNIVERSITY OF LONDON

Institute of Education,  
Psychology and Special Needs Group.  
25, Woburn Square,  
London WC1 HOAA  
Tel: 0171 612 6303  
Fax: 0171 612 66304  
[w.jackson@ioe.ac.uk](mailto:w.jackson@ioe.ac.uk)

UNIVERSITY OF LONDON

Institute of Education

SENJIT

(Courses, training and information to carers and parents)

20 Bedford Way

London WC1H 0AL

Tel: 0207 612 6305/0207 612 6273/4

Fax: 0207 612 6994

UNIVERSITY OF MANCHESTER

School of Education, Centre for Educational Needs,

Oxford Road,

Manchester M13 9PL

Tel: 0161 275 3510

Fax: 0161 275 3548

[cen@man.ac.uk](mailto:cen@man.ac.uk)

UNIVERSITY OF GLASGOW

Resource Centre for the Visually Impaired

105 Salisbury Road

London NW6 6RH

Tel: 0716248844

UNIVERSITY OF NEWCASTLE

School of Education,

Special Needs Research Centre

Newcastle NE1 7RU

Tel: 0191 222 5672

Fax: 0191 222 8170

[c.l.redden@ncl.ac.uk](mailto:c.l.redden@ncl.ac.uk)

UNIVERSITY OF NOTTINGHAM

Blind Mobility Research Unit

Department of Psychology

University Park

Nottingham NG7 2RD

UNIVERSITY OF PORTSMOUTH

Department of Psychology

The Sarah Duffen Centre

Belmont Street, Southsea,

Hampshire PO5 1NA

Tel 44(0) 1705 824261

Facsimile: 44(0) 1705 824265

[www.donset.org/downsed/](http://www.donset.org/downsed/)

[enquiries@downsnet.org](mailto:enquiries@downsnet.org)

UNIVERSITY OF BRISTOL

Access for deaf students initiative

22, Berkeley Square

Bristol BS8 1HP

Tel: 272303030

UNIVERSITY OF WESTMINSTER

Computer Centre for People with Disabilities

72 Great Portland Street

London W1N 5AL

[www.wmin.ac.uk/ccpd/](http://www.wmin.ac.uk/ccpd/)

[d.b.laycock@westminster.ac.uk](mailto:d.b.laycock@westminster.ac.uk)

## **SPORT ASSOCIATIONS FOR PEOPLE WITH LEARNING DISABILITY**

### **UK SPORTS ASSOCIATION**

Ground Floor, Leroy House  
436 Essex Road  
London N1 3QP  
Tel: 020 7354 1030  
Fax: 020 7354 2593  
Contact: Geoff Smedley (Chief Executive)  
Tracey McCillen (National Office Manager)

UKSA Contacts for home country co-ordinating bodies sport and people with learning disability:

### **ENGLAND**

Roger Turner; Chairman  
ESAPLD, Unit 9, Milner Way, Ossett, Wakefield  
W Yorkshire WF5 9JN  
Tel: 01924 267555  
Fax: 01924 267666

### **NORTHERN IRELAND**

Noel Logan  
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### **UNITED KINGDOM SPORTS ASSOCIATION**

for People with L.D.  
Solecast House, 13-27 Brunswick Place,  
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Tel: 0171 250 1100

BRITISH AMPUTEES AND LES AUTRES SPORTS ASSOCIATION  
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BRITISH BLIND SPORT

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[blindsport@btinternet.com](mailto:blindsport@btinternet.com)

BRITISH DEAF SPORTS COUNCIL

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Tel: 01943 850081 (DCT)  
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BRITISH PARALYMPIC ASSOCIATION

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Fax: 020 8681 9650  
[paralympics@compuserve.com](mailto:paralympics@compuserve.com)

BRITISH WHEELCHAIR SPORTS FOUNDATION  
BWSF

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Head of Public Relations  
Guttman Sports & Leisure Centre  
Guttmann Road  
Sotke Mandeville  
Bucks HP21 9PP  
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Fax: 01296 424171  
[wheelpower@dialpipex.com](mailto:wheelpower@dialpipex.com)

DISABILITY SPORT ENGLAND

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Fax: 020 7490 4914  
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**DISABILITY SPORTS NORTHERN IRELAND**

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Belfast BT7 3JH  
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**ENGLISH FEDERATION OF DISABILITY SPORT**

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**ENGLISH FEDERATION OF DISABILITY SPORT  
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Sports Development Centre,  
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London Sports Forum for Disabled People  
Ground Floor, Leroy Business Centre,  
436 Essex Road  
London N1 3QP  
Tel: 020 7354 8666  
Fax: 020 7354 8787  
M-Com: 020 7354 9554

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**SDO Centre, University of Durham,**  
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**Leazes Road, Durham DH1 1TA**

**North West**

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Mobile: 07974 418538**

**South East**

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University of Brighton, Falmer  
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Fax: 01273 643520  
Mobile: 07971 784251**

**South**

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Slough Borough Council,  
Community Service Department  
Twon Hall, Bath Road, Slough SL1 3UQ  
Tel: 01732 873579  
Fax: 01753 875419 Mobile: 07970 722342**

**South West**

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Bristol City Council, Leisure Services  
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Bristol BS1 5AX  
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Fax: 0117 922 3735**

**West Midlands**

**Dennis Hodkins  
Sport & Disability - West Midlands  
26 Woodbury  
University College Worcester  
Henwick Grove  
Worcester WR2 6AJ  
Tel: 01905 855 429  
Fax: 01905 855 432  
Mobile: 07788 746150**

**Yorkshire & Humberside**

**Federation of Disability Sports Organisations  
Unit 9, Milner Way  
Ossett  
West Yorkshire WF5 9JN  
Tel: 01924 279305  
Fax: 01924 280232**

**FEDERATION OF SPORTS ASSOCIATIONS FOR THE DISABLED -WALES-**

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Tel: 01873 830533  
Fax: 01873 830533**

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**Chelmsford**  
**Essex CM1 3NH**  
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**NATIONAL FEDERATION OF GATEWAY CLUBS**  
**Julie Fitzgerald;Director**  
**Mencap**  
**123 Golden Lane.**  
**London EC1Y 0RT**  
**Tel: 020 7454 0454**  
**Fax: 020 7608 3254**

**PLAY MATTERS**  
**68 Churchway**  
**London NW1 1LT**  
**(Information on play and leisure for children and adults with special needs)**

**SCOPE - Cerebral Palsy Sport**  
**Shirley Hughes**  
**Manager**  
**11 Churchill Park**  
**Colwick**  
**Nottingham NG4 2HF**  
**Tel: 0115 9401202**  
**Fax: 0115 9402984**

**SCOTTISH SPORTS ASSOCIATION FOR THE DISABLED**  
**Richar Brickley**  
**Fife Institute of Physical and Recreational Education**  
**Viewfield Road**  
**Glenrothes**  
**Fife KY6 2RA**  
**Tel: 01592 771700**

**SPECIAL OLYMPICS UK**  
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**Chief Executive**  
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**Fax: 0171 735 4639**



## **PUBLICATIONS**

### **BRITISH JOURNAL OF LEARNING DISABILITIES**

BILD Publications  
Frankfurt Lodge  
Clevedon Hall, Victoria Road,  
Clevedon BS21 7HH  
Tel: 01275-876519  
Fax: 01275-3403396

### **SCOPE**

12 Park Crescent  
London W1N 4EQ  
Disability NOW  
(Published by Scope  
[www.disabilitynow.org.uk](http://www.disabilitynow.org.uk))

### **THERAPY WEEKLY**

EMAP Healthcare  
Greater London House  
Hampstead Road  
London NW1 7EJ  
Tel: 0171 874 0200

### **SNIP**

Specific Needs Information Press  
Spring Cottage, Baggot Street  
Abbots Bromly  
Staffordshire WS15 3DA  
Fax: 01283 840 824  
[Carol@sniponline.demon.co.uk](mailto:Carol@sniponline.demon.co.uk)

### **LISTENING BOOKS**

12 Lant Street  
London SE1 1QH  
(Books on tape for people with disabilities)

### **SUPPORT IN TOUCH TRUST**

10 Norman Road  
Sale M33 3DF  
(Puts families of children with special needs in contact with each other)

### **FAMILY INFORMATION GROUP**

4 Oakfield Drive  
Derry BT48 9BG  
NORTHERN IRELAND

## **SPECIAL SOFTWARE SUPPLIERS**

### **ABILITY NET NORTH WEST**

Glaxo Neurological Centre  
Norton Street  
Liverpool L3 8NR  
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[abnnw@seren.demon.co.uk](mailto:abnnw@seren.demon.co.uk)

WIDGET SOFTWARE  
102 Radford House  
Leamington Spa  
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Tel: 01926 885303  
Fax: 019226 885293  
[widget@widgetsw.demon.co.uk](mailto:widget@widgetsw.demon.co.uk)

SEMERC  
1 Broadbent Road  
Wattersheddings  
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Tel: 0161 6274469  
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[sales@semerc.demon.co.uk](mailto:sales@semerc.demon.co.uk)

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Fax: 01509 672267  
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INCLUSIVE TECHNOLOGY  
Saddleworth Business Centre  
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Fax: 01457 819799

TOPOLOGIKA SOFTWARE  
1 South Harbour  
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Tel: 01326 377771  
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[sales@topolgka.demon.co.uk](mailto:sales@topolgka.demon.co.uk)

SHERSTON SOFTWARE  
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XAVIER SOFTWARE  
School of Psychology  
University of Wales, Bangor  
Gwyneth LL57 2DG  
Tel: 01248 382616  
<http://xavier.bangor.ac.uk>

RICKETT EDUCATIONAL MEDIA  
Great Western House  
Langport  
Somerset  
TA10 9NA  
<http://www.r-e-m.co.uk>

REMTEK BUSINESS EQUIPMENT  
Unit 42  
Salford University Business Park  
Frederick Road, Salford  
M6 6AJ  
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Fax: 0161 745 8343  
[john@remtek.u-net.com](mailto:john@remtek.u-net.com)

## ***SPECIFIC CONDITIONS AND SYNDROMES IN CHILDREN WITH THEIR FAMILY SUPPORT NETWORKS***

### **ACNE**

The Ace Support Group  
PO Box 230  
Hayes UB4 0UT  
Tel: 0181 561 6868  
[asg@the.asg.demon.co.uk](mailto:asg@the.asg.demon.co.uk)

### **ACNE SUPPORT GROUP**

1st Floor Howard House  
The Runway South Ruislip  
Middlesex H14 6SE  
[www.stopspots.org.uk](http://www.stopspots.org.uk)

### **ACQUIRED APLASTIC ANAEMIA (aAA)**

Mrs Bryony Dettmar  
Aplastic Anaemia Support Group  
16 Sidney Road  
Borstal  
Rochester ME1 3HF  
Tel: 01634 844062

### **ADAMS-OLIVER SYNDROME**

Adams-Oliver Syndrome Support Group  
11 Berry Place  
Fairwater Cardiff CF5 3LQ  
Tel: 01222 561388

### **ADDISON DISEASE**

Mrs Deana Kenward  
Addison's Disease Self Help Group  
21 George Road  
Guilford GU1 4NP  
Tel: 01483 830673

### **ADRENOLEUKODYSTROPHY**

Mr. A. Attia  
ALD Family Support Trust  
36 Baker Street  
London W1M 1DG  
Tel: 0171 224 7112

### **AGENESIS OF THE CORPUS CALLOSUM/AICARDI SYNDROME CORPAL**

88 Reepham  
Orton Brimbles  
Peterborough PE2 5TT  
Tel: 01733 769912

### **ALBINISM**

Mark Sanderson  
Albino Fellowship  
PO Box 77  
Burnley BB11 5GN  
Tel: 01282 771900 (evenings)

#### ALLERGIES

Action Against Allergy  
PO Box 278  
Twickenham TW1 4QQ

Mrs. Eunice Rose

National Society for Research into Allergies and Environmental Diseases  
PO Box 45  
Hinckley LE10 1JY  
Tel: 01455 851546  
[allergy@pipex.dial.com](mailto:allergy@pipex.dial.com)  
[nsra.allergy@virgin.net](mailto:nsra.allergy@virgin.net)

#### ALPHA THALASSAEMIA MENTAL RETARDATION ON THE X-CHROMOSOME

Denise and David Walker  
ATR-X Support Group  
82 The Crescent  
Northwich CW9 8AD  
Tel: 01606 44943

#### ALTERNATING HEMIPLEGIA

Mrs Gillian Bailey  
Alternating Hemiplegia Support Group  
80 London Road  
Datchet  
Slough SL3 9LQ  
Tel: 01753 546268

#### ANAPHYLAXIS

The Anaphylaxis Campaign  
The Ridges  
2 Clockhouse Road  
Farnborough  
GU14 7QY  
Tel: 01252 542029

#### ANDERSON-FABRY DISEASE

Mrs Suzanne Hill  
Fabry's Disease Research Group  
10 Broadmeadow Road  
Wyke Regis  
Weymouth  
Dorset DT4 9BS  
Tel: 01305 774443

#### ANDROGEN INSENSITIVITY SYNDROME

Androgen Insensitivity Syndrome Support Group  
PO Box 269  
Banbury OX15 6YT  
Tel: 01295 670140

#### ANENCEPHALY

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Anencephaly Support Group  
29 Hawwood Close  
Malvern WR14 1QU  
Tel: 01684 573974

ASSERT (Angelman Syndrome Support Education and Research Trust)  
PO Box 505  
Sittingbourne  
ME10 1NE  
Tel: 01980 652617

Mrs Sheila Woolven  
Angelman Syndrome Support Group  
15 Place Crescent  
Waterville  
Portsmouth  
PO7 5UR  
Tel: 01705 264224

ANKYLOSING SPONDYLITIS  
National Ankylosing Spondylitis Society  
PO Box 179  
Mayfield  
TN20 6ZL  
Tel: 01435 873527. Fax: 01435 873027  
[nasslon@aol.com](mailto:nasslon@aol.com)

ANAPHTHALMIA  
M.A.C.S.  
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Frinton-on-Sea CO13 ORN  
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National Phobics Society  
407 Wilbraham Road  
Chorlton  
Manchester  
M21 0UT  
TelFax: 0161 881 1937

ARTHRITIS (JUVENILE IDIOPATHIC)  
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Children's Chronic Arthritis Association  
47 Battenhall Avenue  
Worcester WR5 2HN  
Tel: 0195 763556

Lady Hoare Trust for Physically Disabled Children  
87 Worship Street  
London EC2A 2BE  
Tel: 0171 377 7567  
Fax: 0171 247 4705

ARTHRITIS CARE  
18 Stephenson Way  
London NW1 2HD

ARTHROGRYPOSIS  
Mrs Diana Piercy  
The Arthrogryposis Group (TAG)  
1 The Oaks  
Gillingham SP8 4SW

**ASTHMA**  
**National Asthma Campaign**  
**Providence House, Providence Place**  
**London N1 0NT**

## Allergy, Asthma & Immunology Online

<http://allergy.mcg.edu/home.html>

(Compiled by the American College of Allergy, Asthma & Immunology this site is described as an information and new centre for patients, parents, professionals and the media).

American Academy of Allergy, Asthma and Immunology

<http://www.aaaai.org/>

(An on-line patient and public resource centre containing a range of asthma education materials).

Asthma & Allergy Information and Research

<http://www.users.globalnet.co.uk/~aaair/>

(UK based web site providing comprehensive information relating to asthma and allergies).

Asthma Resource Centre

<http://www.lung.ca/asthma/index.html>

(Published by the Canadian Lung Association this site includes a series of presentations on asthma management, asthma & exercise, allergies, nutrition, asthma at school, asthma & pregnancy and asthma medications).

Doctor's guide to the Internet: Asthma

<http://www.pslgroup.com/ASTHMA.HTM>

(The patient version of this American site contains a range of asthma information and resources)

European Federation of Asthma & Allergy Associations

<http://www.efanet.org>

(EFA is the European Federation of Asthma and Allergy Associations).

American Lung Foundation

<http://www.lungsa.org/asthma/>

Mothers of Asthma Inc.

<http://www.aanma.org>

Asthma Society of Canada

<http://207.29.250/asthma/>

National Asthma Campaign, Australia

<http://www.nationalasthma.org.au>

GlobalInitiative for Asthma

<http://www.ginasthma.com>

**ATAXIA-TELANGIECTASIA**

**Mrs Helen Hart**

**A-T Society**

**32 Blackford Avenue**

**Edinburg EH9 299**

**Tel: 0131 667 4065**

**ATTENTION DEFICIT HYPERACTIVITY DISORDER**  
**Hyperactive Children's Support Group**  
**71 Whyke Lane**  
**Chichester PO19 2KD**  
**Tel: 01903 725182**

**A.D.D.-A.D.H.D. Family Support Group**  
**1a High Street**  
**Dilton Marsh**  
**Westbury BA13 4DL**  
**Tel: 01373 826045**

**AUTISM**  
**The National Autistic Society**  
**Headquarters, 393 City Road**  
**London EC1V 1NE**  
**Tel: 020 7833 2299**  
**Fax: 020 7833 9666**  
[www.oneworks.org/autism-uk/](http://www.oneworks.org/autism-uk/)  
[nas@nas.org.uk](mailto:nas@nas.org.uk)

The National Autistic Society in Scotland  
2nd Floor, Forsyth House  
111 Union Street  
Glasgow G1 3TA  
Tel: 0141 221 8090  
Fax: 0141 221 8118  
[scotland@nas.org.uk](mailto:scotland@nas.org.uk)

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[jdouglas@nas.org.uk](mailto:jdouglas@nas.org.uk)

The Scottish Society for Autistic Children  
Hilton House  
Alloa Business Park  
Whins Road  
Alloa FK10 3SA

The National Autistic Society Welsh Office  
William Knox House  
Suite C1 Britannic Way  
Llandarcy, Neath  
West Glamorgan SA10 6EL  
Tel: 01792 815915  
Fax: 01792815911  
[wales@nas.org.uk](mailto:wales@nas.org.uk)

The International Autistic Research Organisation  
49 Orchard Avenue  
Croydon CRO 7NE  
Tel: 020 877 0095  
Fax: 020 876 2362  
[www.charitynet.org/iar](http://www.charitynet.org/iar)  
[iarno@lineone.net](mailto:iaro@lineone.net)  
<http://www.yell.co.uk/sites/int-autisticresearch>



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Avon BS12 7BD  
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Fax: 0117 987 2576

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Development and Outreach and Training  
Castle Heights  
4th Floor  
72 Maid Marian Way  
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Tel: 0115 911 3360  
Fax: 0115 911 2259  
[development@nas.org.uk](mailto:development@nas.org.uk)

NAS Volunteering Network  
4th Floor, Castle Heights  
72 Maid Marian Way  
Nottingham NG1 6BJ  
Tel: 0115 9113369  
Fax: 0115 911 3362  
[crintoul@nas.org.uk](mailto:crintoul@nas.org.uk)

The Centre for Social and Communication Disorders  
Eliot House  
113 Masons Hill  
Bromley  
Kent BR2 9HT  
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Fax: 0181 466 0118

BECKWITH-WIEDEMANN SYNDROME  
Bob Baker  
Boeckwith-Wiedemann Group  
The Drum and Monkey  
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Tel: 01258 817573 (Ev)  
Fax: 01305 760985  
[rbaker5165@aol.com](mailto:rbaker5165@aol.com)

BLADDER EXSTROPHY  
Mrs Irene Hall  
BEES Support Group  
4 Durban Road  
Wallasey L45 7NS  
Tel: 0151 200 9795

BRAIN TUMOURS  
Braun Tumours Foundation  
PO Box 162  
New Malden KT3 3YN  
Tel: 0181 336 2020

BRITTLE BONE DISEASES  
OSTEOGENESIS IMPERFECTA

Brittle Bone Societ  
30 Guthrie Street  
Dundee DD1 5BS  
Tel: 0800 282459  
Fax: 01382 206771  
[bbs@brittlebone.org](mailto:bbs@brittlebone.org)

BRONCHO PULMONARY DYSPLASIA  
BLISS

17-21 Emerald Street  
London WC1N 3QL  
Tel: 0171 831 9393  
Fax: 0171 404 0676  
[blissbaby@ukonline.co.uk](mailto:blissbaby@ukonline.co.uk)

CANCER AND LEUKAEMIAS

The Christian Lewis Trust  
Child Care Centre  
62 Walter Road  
Swansea SA1 4PT  
Tel 01792 480500  
Fax: 01792 480700

CLIC

12-12 King Square  
Bristol BS2 8JH  
Tel: 0117 924 8844  
Fax: 0117 924 4505  
[operations@sargent.org.uk](mailto:operations@sargent.org.uk)

CYSTIC FIBROSIS TRUST

11 London Road  
Bromley, Kent BR1 1BY  
Tel: 020 8464 7211  
Fax: 020 8313 0472

Edward's Trust

Edward House, St Mary's Row  
Birmingham B4 6NY  
Tel: 0121 237 5656  
Fax: 0121 237 5657

CARDIOMYOPATHIES

Cardiomyopathy Association  
40 The Metro Centre  
Tolpits Lane  
Watford, WD1 8SB  
Tel: 01923 249977  
Fax: 01923 249987

CEREBELLAR ATAXIA

Ataxia Group  
The Stable, Wiggins Yard  
Bridge Street  
Godalming GU7 1HW  
Tel: 01483 417111  
Fax: 01483 424006

CEREBRAL PALSY  
SCOPE  
6-10 Market Road  
London N7 0PW

CEREBRAL PALSY HELPLINE  
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Helpline: 0808 800 3333  
[www.scope.org.uk](http://www.scope.org.uk)  
[cphelpline@scope.org.uk](mailto:cphelpline@scope.org.uk)

Capability Scotland  
ASCS  
11 Ellersly Road  
Edinburg EH12 6HY  
Tel: 0131 313 5510  
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Crisp Service, NICOD  
Malcolm Sinclair House  
31 Oulsterville Avenue  
Lisburn Road  
Belfast BS9 7AS

Scottish Centre for Children with Motor Impairments  
1 Craighalbert Way  
Cumbernauld, Glasgow G68 0LS  
Tel: 01236 456100  
Fax: 01236 736889  
[106456.2073@compuserve.UK](mailto:106456.2073@compuserve.UK)

CHARCOT-MARIE-TOOTH DISEASE  
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115 Boundary Road  
Colliers Wood  
London SW19 2DE  
Tel: 0181 540 2142  
(congenital defects)

CHROMOSOME DISORDERS  
Unique- The Rare Chromosome Disorder Support Group  
PO Box 2189  
Caterham CR3 5GN

CHRONIC GRANULOMATOUS DISORDER  
CGD Support Group/Research Trust  
Manor Farm  
Wimborne St. Giles  
Wimborne BH21 5NL

#### CLEFT LIP AND/OR PALATE

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#### COELIC DISEASE

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Facsimile: 01270 25044

[www.climb.org.uk](http://www.climb.org.uk)

#### COHEN SYNDROME

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#### COLOBOMA

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#### CONGENITAL ABSENCE OF THE TESTES

Anorchidims Support Group

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Romford RM3 8GX

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#### CONGENITAL ADRENAL HYPERPLASIA

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Bedford MK45 1PX

Tel: 01525 717536

[cahg.rtmde@mculldemon.co.uk](mailto:cahg.rtmde@mculldemon.co.uk)

#### CONGENITAL CENTRAL HYPERVENTILATION SYNDROME

Ondine's Support Group

24 Larners Road

Tofwood, Dereham NR19 1LE

Tel: 01362 696509

#### CONGENITAL DISLOCATION OF THE HIP

Mrs Sue Banton

##### STEPS

Lymm Court, 11 Eagle Brow

Lymm WA13 0LP

[steps@itl.net](mailto:steps@itl.net)

#### CONGENITAL MUSCULAR DYSTROPHY

Mrs Marion West. Cmd Support

21 Morrison Drive. Pitcorthie

Dunfermline KY11 5DJ

Tel: 01383 736084

[cmd@globalnet.co.uk](mailto:cmd@globalnet.co.uk)

#### CONGENITAL NEUTROPENIA

The Primary Immunodeficiency Association

Alliance House

12 Caxton Street

London SW1H 0QS

Tel: 0171 976 7640

#### CONGENITAL OCULAR MOTOR APRAXIA

Mrs Ros Evans

COA Support Group

20 Sheridan Road

Whipton

Exeter EX4 8EY

Tel: 01392 460618

#### CORNELEA DE LANGE SYNDROME

Mr Alan Peaford

CDLS Foundation UK

"Tall Trees" 106 Lodge Lane

Grays RM16 2UL

Tel: 01375 376439

#### COT DEATH

Foundation for the Study of Infant Deaths

14 Kalkin Street

London SW1X 7DP

Tel: 0171 235 0965

Fax: 0171 823 1986

[fsid@dial.pipex.com](mailto:fsid@dial.pipex.com)

#### CRANIOFACIAL CONDITIONS

Steve & Erica Moody

44 Helmsdale Road

Leamington Spa CV32 7DW

Tel: 01926 334629

[100130.1636@compuserve.com](mailto:100130.1636@compuserve.com)

#### CREUTZFELDT-JAKOB DISEASE

National CJD Co-ordinator

Creutzfeld-Jakob Disease Support Network

Birchwood, Health Top, Ashely Heath

Market Drayton TF9 4QR

Tel: 01630 673993

#### CRI DU CHAT SYNDROME

Mrs Angie Stokes  
Cri du Chat Syndrome Support Group  
7 Penny Lane  
Barwell, Leicester LE9 8HJ  
Tel: 01455 841680

#### CROHN'S DISEASE AND ULCERATIVE COLITIS

Mrs Margaret Lee  
Crohn's in Childhood Research Association  
Parkgate House, 356 Wets Barnes Lane  
Motspur Park  
New Malden KT3 6NB  
Tel: 0181 949 6209

#### CUSHING SYNDROME/DISEASE

Val Howarth  
Cushing Care  
Meadows, Woodplumton Village  
Preston PR4 0LJ  
TeleFax: 01772 690680

#### CYCLICAL VOMITING

Mrs Nicola Kipping  
CVSA  
5 Anthonys Avenue  
Lilliput Poole BH14 8JQ  
Tel: 01202 709194

#### CYSTIC FIBROSIS

Family & Adult Support Services Cystic Fibrosis Trust  
11 London Road  
Bromley BR1 1BY  
Tel: 0181 464 7211  
Fax: 0181 313 0472

#### CYSTIC HYGROMA

Mrs Pearl Fowler Cystic Hygroma Support Group  
Villa Fontana, Church Road  
Worth, Crawley RH10 7RS  
Tel: 01293 885901  
Fax: 01293 882460

#### DANCING EYE SYNDROME

Mrs Jane Stanton-Roberts  
Dancing Eye Syndrome Support Trust  
78 Quantock Road  
Worthing BN13 2HQ  
Telfax: 01903 532383  
[rasr@mistral.co.uk](mailto:rasr@mistral.co.uk)

#### DEAFBLIND/RUBELLA DAMAGED

Sense, 11-13 Clifton Terrace  
Finsbury Park  
London N4 3SR  
Tel: 0171 272 7774 Fax: 0171 272 6012  
[www.sense.org.uk](http://www.sense.org.uk)  
[enquiries@sense.org.uk](mailto:enquiries@sense.org.uk)

Sense Northern Ireland  
Family Centre  
Manor House  
51 Mallusk Road  
Nowtownabbey BT36 4RU

DEAFNESS  
The National Deaf Children's Society  
15 Dufferin Street  
London EC1Y 8UR  
Tel: 0171 250 0123  
Fax: 0171 251 5020  
[ndcs@ndcs.org.uk](mailto:ndcs@ndcs.org.uk)

Breakthropugh Deaf/Hearing Integration  
Alangale House, The Close  
West Hill Campus, The Close  
West Hill Campus, Bristol Road  
Birmingham B29 6LN  
Fax: 0121 4152323  
[www.breakthriugh.dhi.org.uk](http://www.breakthriugh.dhi.org.uk)  
[admin@breakthrough-dhi-org.uk](mailto:admin@breakthrough-dhi-org.uk)

Hearing Aided Young Adults  
7-11 Armstrong Road  
London W3 7JL

DERMATOMYOSITIS AND POLYMYOSITIS  
Mr Les and Mrs Irene Oakley  
Dermatomyositis and Polymyositis Support Group  
146 Newton Road  
Woolston  
Southampton  
SO19 9HR  
Tel: 0170 449708  
Fax: 01703 396402

DIABETES MELLITUS  
Youth and Family Services  
British Diabetic Association  
10 Queen Anne Street  
London W1M 0BD  
Tel: 0171 323 1531

DIAMOND BLACKFAN ANAEMIA SYBNDROME  
Diamond Blackfan Anaemia Support Group  
44 Helmsley Road  
Halewood  
Liverpool L26 0SY  
Tel: 0151 448 1446

DUCHENNE MUSCULAR DYSTROPHY  
Duchenne Family Support Group  
97 Torrington Park  
London N12 9Pn  
Tel: 0171 704 9142

#### DYSKERATOSIS CONGENITA

Mark Stewart  
Dyskeratosis Congenita Society  
10 Cairnwell Crescent  
Montrose DD10 9EY  
Tel: 01674 675578

#### DYSTONIA

The Dystonia Society - Young Dystonia  
46-47 Britton Street  
London EC1M 5UJ  
Tel: 0171 490 5671  
Fax: 0171 329 0689

#### EATING DISORDERS

Eating Disorders Association  
First Floor, Wensum House  
103 Prince of Wales Road  
Norwich, Norfolk NR1 1DW  
media: 01603 624 310  
[www.gurney.otg.uk.eda/](http://www.gurney.otg.uk.eda/)  
[eda@net.com.co.uk](mailto:eda@net.com.co.uk)  
(anorexia nervosa and bulimia nervosa)

#### OVEREATERS ANONYMOUS

P.O. Box 19,  
Stretford, Manchester M32 9EB  
Tel: 07000 784985  
(For information about help available nationally)

#### DEPRESSIVES ANONYMOUS

36 Chesnut Avenue  
Beverley, East Yorkshire  
HU17 7QU  
Tel: 01482 860 619

#### DEPRESSION ALLIANCE

35 Westminster Bridge Road,  
London, SE1 7JB  
Tel: 0171 721 7411

#### SIZE

Suite 147  
56 Gloucester Road,  
London  
SW7 4AU  
(This organisation provides size acceptance information and has a magazine called Freesize.)

#### ECTODERMAL DYSPLASIA

British Ectodermal Dysplasia Support Group  
108 Charlton Lane  
Cheltenham GL53 9EA  
Tel: 01242 231754

#### ECZEMA

National Eczema Society  
163 Everholt Street  
London NW1 1BU  
Tel: 0171 388 4097. Fax: 0171 388 5882



#### EDWARDS SYNDROME

Christine Rose  
SOFT UK  
48 Froggatts Ride  
Sutton Coldfield B76 2TQ  
Tel: 0121 351 3122 or 0121 351 5728

#### EHLERS-DANLOS SYNDROME

Mrs Valerie Burrows  
Ehlers-Danlos Syndrome Support Group  
1 Chandler Close  
Richmond DL10 5QQ  
Telefax: 01748 823867  
[EDS-UK@compuserve.com](mailto:EDS-UK@compuserve.com)

#### ELLIS-VAN CREVELD SYNDROME

Mrs Yvonne Sutton  
Ellis-Van Cleveld Foundation  
Farthingale Farm  
Hackmans Lane  
Purleigh  
Chelmsford CM3 6RW  
Tel: 0121 829675

#### ENCEPHALITIS

Encephalitis Support Group  
44a Market Place  
Malton  
North Yorkshire  
YO17 7LH  
Tel/Fax: 01653 699599  
[www.glaxocentre.merseyside.org/enceph.html](http://www.glaxocentre.merseyside.org/enceph.html)  
[encephalitissupportgroup@compuserve.com](mailto:encephalitissupportgroup@compuserve.com)

#### ENURESIS

Enuresis Resource & Information Centre  
34 Old School House  
Britannia Rd, Kingswood  
Bristol BS15 8DB

#### EPIDERMOLYSIS BULLOSA

DEBRA  
DEBRA House  
13 Wellington Business Park  
Dukes Ride  
Crowthorne RG24 6LS  
Tel: 01344 771961  
Fax: 01344 762661

#### EPILEPSY

The National Society for Epilepsy  
Chalfont St. Peter  
Gerrards Cross, Bucks  
SL9 0RJ  
Tel: 01494 601300  
Fax: 01494 871927  
<http://www.erg.ion.aicl.ac.uk/NSEhome>

British Epilepsy Association  
Anstey House 40 Hanover Square  
Leeds LS3 1BE  
Tel: 0113 210 8800  
Fax: 0113 391 0300  
[www.epilepsy.org.uk](http://www.epilepsy.org.uk)  
[epilepsy@bea.org.uk](mailto:epilepsy@bea.org.uk)

The Epilepsy Association of Scotland  
48 Govan Road  
Glasgow G51 1JL  
Tel: 0171 427 4911  
Fax: 0171 427 2747

ERB'S PALSY  
Erb's Palsy Support Group  
2 Willoughby Close  
Coventry CV3 3GJ  
Tel: 61203 452321

FACIAL DISFIGUREMENT  
Mrs Christine Piff  
Junior Let's Face It  
14 Fallowfield  
Yateley  
Camberley GU17 7LW  
Tel: 01252 879630  
Fax: 01252 872633  
[mike@Ifi-u-net.com](mailto:mike@Ifi-u-net.com)

CHANCING FACES  
1 & 2 Junction Mews  
Paddington  
London W2 1PN  
Tel: 0171 796 4232  
Fax: 0171 706 4234

FACIOCAPULOHUMERAL MUSCULAR DYSTROPHY  
Mrs Lorraine Jonas  
FSH Muscular Dystrophy Support Group  
2 Hamlyn Close  
Pipers Freen Lane  
Edgware HA8 8DB  
Tel: 0181 958 7888  
Fax: 0181 858 2198

FAMILIAL DYSAUTONOMIA  
Mrs Rosilind Jacobs  
Dysautonomia Society of Great Britain  
41 Francklyn Gardens  
Edgware HA8 8RU  
Tel: 0181 357 0038  
Fax: 0181 958 8760

FAMILIAL HYPERLIPIDAEMIAS  
Family Heart Association  
7 North Road  
Maidenhead SL6 1PL  
Tel: 01628 28638

**FAMILIAL SPASTIC PARAPLEGIA**

Stephanie Poengally  
FSP Group  
37 Alexandra Road  
Great Wakering  
South-on-Sea SS3 0HN  
Tel: 01702 218184

**FANCONI'S ANAEMIA**

David Westmoreland  
F.A.B. U.K.  
4 Pateley Road  
Woodthorpe  
Nottingham NG3 5QF  
Tel: 0115 926 9634

**FETAL ABNORMALITY**

ARC  
73-75 Charlotte Street  
London W1P 1LB  
Tel: 0171 631 0285  
TeleFax: 0171 631 0280  
[arcsatfa@aol.com](mailto:arcsatfa@aol.com)

**FETAL ALCOHOL SYNDROME**

Fetal Alcohol Syndrome Trust  
15 Wasdale Road  
Aintree, Liverpool L9 8AS  
TeleFax: 0151 284 2900

Mrs. Margaret Murch

P.O. Box 30  
Walton, Liverpool L9 8HU  
[margaret@fastrust.freemove.co.uk](mailto:margaret@fastrust.freemove.co.uk)

**FETAL ANTI-CONVULSANT SYNDROME**

National Fetal Anti-Convulsant Syndrome Association  
Newton of Brux  
Glenkindie  
Alford AB33 8RX  
Tel: 019755 71340  
[FACSLINE@aol.com](mailto:FACSLINE@aol.com)

**FLOATING-HARBOR SYNDROME**

Mrs Sue Sinclair  
Floating-Harbor Syndrome Contact Group  
27 Hatfield Road  
Dagenham, Essex RM9 6JR  
Tel: 081 517 6842

**FRAGILE X SYNDROME**

Mrs Lesley Walker  
Fragile X Society  
53 Winchelsea Lane  
Hastings TN35 4LG  
Tel: 01424 813147  
[www.fragile.org.uk](http://www.fragile.org.uk)  
[lesleywalker@fragile.k-wcb.co.uk](mailto:lesleywalker@fragile.k-wcb.co.uk)

Anne Langford  
Lacertas  
26 Lower St Hellens Rd.  
Hedge end  
Southampton  
SO30 OLW  
Tel: 01489 786739

FRIEDREICH'S ATAXIA  
and all inherited ataxias  
Ataxia Group  
The Stable  
Wiggins Yard  
Bridge Street  
Godalming GU7 1HW  
Tel: 0143 417111  
Fax: 0143 424006

GALACTOSAEMIA  
Mrs Susan Bevington  
Galactosaemia Support Group  
31 Cotysmore Road  
Sutton Coldfield  
West Midlands B75 6BJ  
Tel: 0121 378 5143

GAUCHER DISEASE  
Mrs Susan Lewis  
Dauchers Association  
25 Wets Cottages  
London NW6 1RJ  
Tel: 0171 433 1121

GLANZMANN'S THROMBASTHENIA  
Marilyn Buxton  
Glanzmann's Thrombasthenia Contact Group  
28 Duke Road  
Newton. Hyde  
Cheshire SK14 4JB  
Tel: 0161 368 0219

GLAUCOMA  
TADPOLES  
65 Busbarns  
West Cheshunt EN7 6ED  
International Glaucoma Association  
[iga@kcl.ac.uk](mailto:iga@kcl.ac.uk)

GLYCOGEN STORAGE DISEASES  
Mrs Ann Phillips  
The Association for Glycogen Storage Diseases (UK)  
9 Lindop Road  
Hale  
Altrincham  
WA15 9DZ  
Tel: 0161 980 7303  
Fax: 0161 226 3813  
[ae314@dial.pipex.com](mailto:ae314@dial.pipex.com)

#### GOLDENHAR SYNDROME

Nicola Woodgate  
Goldenhar Syndrome Support Group  
9 Hartley Court Gardens  
Cranbrook TN17 3QY  
Tel: 01580 714042

#### GORLIN SYNDROME

Mr Jim Costello  
Gorlin Syndrome Group  
11 Blackberry Way  
Penwortham, Preston PR1 9LQ  
Tel: 01772 496849

#### GROUPS B STREPTOCOCCUS

Jane and Robert Plumb  
Groups B Strep Support  
PO Box 203  
Haywards Heath RH16 1GF  
Tel: 01444 416176  
[info@gbss.org.uk](mailto:info@gbss.org.uk)

#### GROWTH HORMONE DEFICIENCY

Growths Hormone Deficiency/MPHD Support Group  
c/o Child Growth Foundation  
2 Mayfield Avenue, Chiswick  
London W4 1PW  
Tel/Fax: 0181 995 9075

#### GUILLAIN-BARRE SYNDROME and other neuropathies

Guillain-Barre Syndrome Support Group of the United Kingdom  
c/o Lincolnshire County Council  
Eastgate, Sleaford NG34 7EB  
Tel: 01529 304615

#### GUT MOTILITY DISORDERS

Gut Motility Disorders Support Network  
7 Walden Road  
Sewards End  
Saffron Walden CB10 2LE  
Tel: 01799 520580 (ev)

#### HAEMOPHILIA SOCIETY

Chesterfield House  
385 Euston Road  
London NW1 3AU  
Tel: 020 7380 0600  
Fax: 020 7387 8220  
Helpline: 0800 018 6068  
[www.haemophilia.org.uk](http://www.haemophilia.org.uk)  
[info@haemophilia.org.uk](mailto:info@haemophilia.org.uk)

#### HIV INFECTION AND AIDS

Barnardos Positive Options  
Unit 22 Angel Gate  
City Road  
London EC1V 2PT  
Tel: 0171 278 5039

Positively Women  
347-349 City Road  
London EC1V 1LR  
Tel: 0171 713 0444

HAEMOCHROMATOSIS  
Mrs Janet Fernau  
Haemochromatosis Society  
Hollybush House  
Hadley Green Road  
Barnet EN5 5PR  
Tel: 0181 449 1363  
[ghsoc@compuserve.com](mailto:ghsoc@compuserve.com)

HAMOLYTIC URAEMIC SYNDROMES  
HUSH  
PO Box 1303  
Sheffield S6 6YL  
Tel: 0800 731 4679

HAEMOPHILIA, VON WILLEBRAND DISEASE  
and other coagulations defects  
Haemophilia Society  
3rd. Floor, Chesterfield House  
385 Euston Road  
London NW1 3AU  
Tel: 0171 380 0600  
[info@haemophilia-soc.demon.co.uk](mailto:info@haemophilia-soc.demon.co.uk)

HEAD INJURIES  
Children's Head Injury Trust  
c/o Neurosurgery Departament  
Rodcliffe Infirmary, Woodstock Road  
Oxford OX2 6HE  
Tel: 01865 224 786  
[execdir@chit.demon.co.uk](mailto:execdir@chit.demon.co.uk)

HEART & HEART/LUNG TRANSPLANT  
Heart Transplant Families Together  
c/o Cardiomyopathy Association  
40 The Metro Centre  
Watford WD1 8SB  
Tel: 01923 249977 Fax: 01923 249987

Children's Heart Federation  
32 Littleheath  
London SE7 8HU

The Association for Children with Heart Disorders (England and Wales)  
26 Elizabeth Drive  
Helmshore  
Rossendale BB4 4JB

The Association for Children with Heart Disorders (Scotland)  
Killieard House  
Killiecrankie  
Pitlochry PH16 5LN

#### HEMIMEGALENCEPHALY

Dagmar & David Kerr  
HME Contact Group  
3 Linne Drive  
Netherlee  
Glasgow G44 3PT Tel: 0141 633 2617

#### HEMIPLEJIA

Hemi-Help  
2nd Floor Bedford House  
215 Balham High Road  
London SW17 7BQ  
Tel: 0181 767 0319  
[HemiHelp@btinternet.com](mailto:HemiHelp@btinternet.com)

#### HENOCH SCHONLEIN PURPURA

Mrs. Jill Neville  
MSP Contact Group  
97 Moor Lane  
Chessington KT9 1HV. Tel: 0181 287 3317

#### HEREDITARY HAEMORRHAGIC TELANGIECTASIA

Mrs. Diana Lawson  
Telangiectasia Self Help Group  
39 Sunny Croft  
Downley, High Wycombe HP13 5UQ  
Tel: 01494 528047

#### HEREDITARY MULTIPLE EXOSTOSIS SUPPORT GROUP

60 Stevenage Road  
Walkern SG2 7NE  
Tel: 01438 861473  
[hmesg@ox1.co.uk](mailto:hmesg@ox1.co.uk)

#### HIOSTIOCYTOSIS SUPPORT GROUP UK

Fionna Lynch  
23 Maple Grove  
Woburn Sands  
Milton Keynes MK17 8QN  
Tel: 0700 790336

#### HODGKIN'S DISEASE

Lymphoma Association  
P.O. Box 275  
Hoddenham Aylesbury HP17 8JJ  
Tel: 01844 291479  
Fax: 01844 292757

#### HOLOPROSENCEPHALLY SUPPORT GROUP

70 Liphook Road, Lindefor  
Bordon GU35 0PG  
Tel: 0142 473065

#### HOLT-ORAM SYNDROME SUPPORT GROUP

Andrew Sigsworth  
21 Forth Road  
Redcar, Cleveland ST10 1PN  
TeleFax: 01642 50183  
[holt-oram@btinternet.com](mailto:holt-oram@btinternet.com)

HUNTINGTON'S DISEASE ASSOCIATION  
108 Battersea High Street  
London SW11 3HP  
Tel: 0171 723 7000  
Fax: 0171 723 9489

HYDROCEPHALUS  
Association for Spina Bifida & Hydrocephalus (ASBAH)  
ASBAH HOUSE  
42 Park Road  
Peterborough PE1 2UQ  
Tel: 01733 555988  
Fax: 01733 555985  
[www.asbah.demon.co.uk](http://www.asbah.demon.co.uk)  
[postmaster@asbah.demon.co.uk](mailto:postmaster@asbah.demon.co.uk)  
[gillw@asbah.demon.co.uk](mailto:gillw@asbah.demon.co.uk)

HYPERACTIVE CHILDREN'S SUPPORT GROUP  
Mrs. Sally Bunday  
71 Whyke Lane  
Chichester  
Wets Sussex PO19 2LD  
Tel: 0903 725182

THYROID APLASIA SUPPORT GROUP  
Mrs. Caroline Hulme  
47 Crwford Av.  
Tyldesley  
Manchester M29 8ET  
Tel: 01942 874740

ICHTHYOSIS SUPPORT GROUP  
16 Cambridge Avenue  
London NW6 5AB  
Tel: 0171 461 0356

IMMUNE IDIOPATHIC THROMBOCYTOPENIC PURPURA  
ITO -The Support Group  
'Synehurste'  
Kimbolton Road  
Balmurst  
Bedford MK44 2EW  
Tel: 01234 376559

INTESTINAL AND UROLOGICAL CONDITIONS  
John Halcolm  
NASPCS  
51 Anderson Drive  
Valley View Park  
Darvel  
Ayrshire KA17 ODE  
Tel: 0560 322024

IRRITABLE BOWEL SYNDROME  
IBS Network  
Northern General Hospital  
Sheffield S5 7AV  
Tel: 0114 261 1531



**IVEMARCK SYNDROME**

Mrs. I. Gladki  
Ivemark Syndrome Association  
6 Ashbourne Crescent  
Taunton TA1 2RB  
Tel: 01823257430  
[Ingi@Ingrid-Gladki.Freeserve.com.uk](mailto:Ingi@Ingrid-Gladki.Freeserve.com.uk)

**JUVENILE OSTEOPOROSI**

The National Osteoporosis Society  
P.O.Box 10  
Rodstock  
Bath BA3 3XB  
Tel: 01761 471771  
Fax: 01761 471104

**KAWASAKI SUPPORT GROUP**

Sue Davidson  
13 Norwood Grove  
Potters Green  
Conventry CU2 2FR  
Tel: 01203 612178

**KIDNEY DISEASE**

British Kidney Patient Association  
Bordon  
Hants GU35 9JZ  
Tel: 0420 472021

**KLINEFELTER SYNDROME**

Mrs. Sue Cook  
Klinefelter's Syndrome Association  
56 Little Yeldham Rd.  
Little Yeldham  
Halstead cO9 4QT  
TeleFax: 01787 237 460

Klinefelter Syndrome and Associates  
P.O. Box 119  
Roseville, CA 95678-0119

Klinefelter Syndrome  
Steve Hammet  
(Teenager/Adult Contact)  
Klinefelter's Syndrome association  
13 York Rire  
Aysington  
Kent BR6 8PR

**KLIPPEL-TREANUANAY SYNDROME SUPPORT GROUP**

Mrs. Carol Wilson  
9 Newland Avenue.  
Cadworth. Barnsley  
ST2 8UZ  
Tel: 01226 780085  
[zoo02038@zoo.co.uk](mailto:zoo02038@zoo.co.uk)

LANDAU-KLEFFNER SYNDROME

F.O.L.K.S.  
P.O.Box 749  
Erith DA8 3UA  
Tel: 0870 8470707

LAURENCE-MOON-BARDET-BIEDL- SYNDROME SOCIETY

Mrs. Drina Parker  
Spring Grove  
Landhomes Wood Lane  
Chalfont St. Giles HP8 4AR  
Tel: 01494 764924

LEARNING DISABILITY

National Children's Officer  
Mencap  
4 Swan Courtyard  
Coventry Road  
Birmingham B26 1BU

ENABLE

6th Floor, 7 Buchanan Street  
Glasgow G1 3HL  
Tel: 0141 226 4541  
Fax: 0141 204 4398  
[enable@enable.org.uk](mailto:enable@enable.org.uk)

LEBER'S CONGENITAL AMAUROSIS- PLAN

46 Blandford Av.  
Oxford OX2 8DZ  
Tel: 01865 559084  
[deval@pla.demon.co.uk](mailto:deval@pla.demon.co.uk)

LEBER'S OPTIC NEUROPATHY

Mrs. T. Handscombe  
Liber's Office Neuropathy Trust  
13 Palmar Rd.  
Maidstone, Kent ME16 0DL

LENNOX-GASTAUT SUPPORT GROUP

Mr. Andrew Gibson  
9 South View  
Burrough on the Hill  
Milton Mowbroy LE14 2JJ  
Tel: 01664 454305  
(Epilepsy)

LEUKAEMIA

Leukaemia Care  
14 Kingsfisher Court  
Vinnys Bridge  
Pinhoe, Devon EX4 8JN

Leukaemia Research Foundation

43 Great Ormond Street  
London WC1N 3JJ  
Tel: 0171 405 0101  
Fax: 0171 242 1488  
[info@leukaemia-research.org.uk](mailto:info@leukaemia-research.org.uk)

LISSENCEPHALY CONTACT GROUP  
39 Barlow Rd., Edgbaston  
Birmingham B15 2PN  
Tel: 0121 455 0981

**CHILDREN'S LIVER DISEASE FOUNDATION**  
**Axa Equity and Law House**  
**35-37 Great Charles Street, Queensway**  
**Birmingham B3 3JY**

36 Great Charles Street  
Birmingham B3 3JY  
Tel: 0121 212 3839  
Fax: 0121 212 4300  
[www.childliverdisease.org](http://www.childliverdisease.org)  
[info@childliverdisease.org](mailto:info@childliverdisease.org)

LOWE SYNDROME ASSOCIATION  
David & Julie Oliver  
29 Gleneagles Drive, Penwortham Preston  
Lancashire PR1 0JT  
Tel: 0772 745070

Lowe Syndrome Association Inc.  
222 Lincoln Street  
Wets Lafayette, Indiana  
47906.  
Tel: 317 743 3634

LOWER LIMB ABNORMALITIES  
Mrs. Sue Bouton  
STEPS  
Lymm Court  
11 Lymm Eagle Brow  
Lymm Cheshire WA13 0LP  
[www.steps-charity.org.uk](http://www.steps-charity.org.uk)  
[steps@itl.net](mailto:steps@itl.net)

BRITISH LUNG FOUNDATION  
78 Halton Garden  
London EC1 8JR  
Tel: 0171 831 5831 Fax: 0171 831 5832

LUPUS UK  
1 Euston Rd  
Romford RM1 3NH  
Tel: 01708 73125  
Fax: 01708 731252

LYMPHOMA ASSOCIATION  
P.O.Box 386  
Aylesbury  
Bucks HP20 26A  
Fax: 01296 619414  
Helpline: 0800 808 5555  
[www.lymphoma.org.uk](http://www.lymphoma.org.uk)

LYMPHOEDEMA SUPPORT NETWORK

St. Luke's Court  
Sydney Street  
London W3 6NH  
Tel: 01708 731251  
Fax: 01708 731252

BRITISH MALIGNANT HYPERTHERMIA ASSOCIATION

Mrs. Alison Winks  
11 Gorse Close  
Newthorpe  
Nottingham NG16 2BZ  
Tel: 01773 717901 (ev)

MUSCULAR DYSTROPHY CAMPAIGN

7-11 Prescott Place  
London SW4 6BS  
Tel: 020 7720 8055  
Fax: 020 7494 0670  
[www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)  
[info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org)

MYALGIC ENCEPHALOMYELITIS ASSOCIATION  
4 Corringham Rd.  
Stanford-le-Hope  
SS17 0AH  
Tel: 01749 670799

ACTION FOR ME  
P.O.Box 1302  
Wells BA5 2WE

MYASTHENIA GRAVIS ASSOCIATION  
Chester Park  
Alfreton Road  
Derby DE1 4AS  
Tel: 01332 290219

THE MIGRAINE TRUST  
45 Great Ormond Street  
London WC1N 3HZ  
Tel: 020 7831 4818  
Fax: 020 7831 5174

MOEBIUS SYNDROME SUPPORT GROUP  
24 Front Street  
Monkseaton  
Whitley Bay NE25 8DF  
Tel: 0191 253 2090

MOTOR NEURONE DISEASE ASSOCIATION  
P.O. Box 246  
Northampton NN1 2PR  
Tel: 01604 250505  
Fax: 01604 24726

THE SOCIETY FOR MUCOPOLYSACCHARIDE DISEASES  
46 Woodside Road  
Amersham HP6 6AJ  
Tel: 01494 434156  
Fax: 01494 434252  
[MPSUK@compuserve.com](mailto:MPSUK@compuserve.com)

MULTIPLE SCLEROSIS  
MULTIPLE SCLEROSIS RESOURCE CENTRE  
4a Chapel Hill  
Stansted  
Essex CM24 8AG

M.S.  
7 Peartree Business Centre  
Peartree Rd.  
Stauway  
Colchester  
Essex CO3 5JN  
Tel: 01206 509444  
Fax: 01206 505449  
[themsrsrc@yahoo.com](mailto:themsrsrc@yahoo.com)

Multiple Sclerosis Society  
25 Effie Road  
Fulham  
London SW6 1EE  
Tel: 020 7610 7171  
[www.mssociety.org.uk](http://www.mssociety.org.uk)  
[info@mssociety.org.uk](mailto:info@mssociety.org.uk)

MARFAN SYNDROME ASSOCIATION UK  
Rochester House  
5 Aldershot Road  
Fleet  
Hants GU13 9NG  
Tel: 01252 810472  
Fax: 01252 810473

MELNICK - NEEDLESS SYNDROME  
Gill Carter, MNS Support Group  
4 Kinver Lane  
Bexhill on Sea  
East Sussex TN40 2ST  
Tel: 01424 217790

MENINGITIS  
National Meningitis Trust  
Fern House  
Bath Road Stroud  
Gloucestershire  
Glos GL5 3TJ  
Tel/Minicom: 01453 76800  
Fax: 01453 768001  
[www.meningitis-trust.org.uk](http://www.meningitis-trust.org.uk)  
[support@meningitis-trust.org.uk](mailto:support@meningitis-trust.org.uk)

Meningitis Research Foundation  
Midland Way  
Thornbury  
Bristol BS35 2BS  
Tel: 01454 281811  
[www.meningitis.org](http://www.meningitis.org)  
[info@meningitis.org](mailto:info@meningitis.org)

MENTAL HEALTH  
Young Minds  
102-108 Clerkenwell Road  
London EC1M 5SA

MICROCEPHALY SUPPORT GROUP  
22 Auctioneers Court  
Auctioneers Way  
The Old Cattlemarket  
Northampton NN1 1EY  
Tel: 01604 603743

NARCOLEPSY ASSOCIATION (UK)  
2 Bishop's Clove  
Hurstpierpoint  
Hassocks  
BN6 9XU

THE NEUROBLASTOMA SOCIETY

Ann Ward  
41 Towncourt Crescent  
Petts Wood. Kent BR5 1PH

18 Hardlesden Road  
St Albans Herts  
AL1 4LF  
TeleFax: 01727 851818

THE NEUROFIBROMATOSIS ASSOCIATION

82 London Road  
Kingston upon Thames  
KT2 6PX

NIEMANN-PICK DISEASE GROUP (UK)

Mrs. Susan Green  
Kingslow House  
East Brea East Wemyss  
Kirkcaldy KY1 4RR  
Tel: 01592 580672

NOONAN SYNDROME

Family Services Officer  
Birth Defect Foundation  
Martindale, Hanks Green  
Cannock WS11 2XN  
Tel: 01543 468400

NYSTAGMUS NETWORK

RNIB  
190 Kansal Road  
London W10 5BT  
Tel: 0181 968 6161  
[eyesiteJS@msn.com](mailto:eyesiteJS@msn.com)

OHDO SYNDROME FAMILY NETWORK

36 Borrowdale Avenue  
Gattler  
Cheadle SK8 4FQ  
Tel: 0161 428 8583  
Fax: 0161 491 6359  
[sevill@globalnet.con.uk](mailto:sevill@globalnet.con.uk)

OLLIER'S DISEASE SELF-HELP GROUP

Mr. Andrew Harter  
Tithings New Born  
Swalcliffe  
Banbury OX15 5DR  
Tel: 01295 788001  
Fax: 01295 788002

OSTEOPETROSIS

Mrs. Margaret Wright  
Osteopetrosis Support Trust - OST  
10 Cumberland Av.  
Fixby  
Huddersfield HD2 2JJ

NATIONAL OSTEOPOROSIS SOCIETY

P.O. Box 10,  
Radstock, Bath BA3 3YB  
Tel: 01761 47171  
Fax: 01761 471104  
[www.nos.org.uk](http://www.nos.org.uk)  
[info@nos.org.uk](mailto:info@nos.org.uk)

PATAU SYNDROME

Jenny Rolbins  
SOFT UK  
Tudor Lodge  
Redward  
Rasson Wye HR9 5UD

PERTHES DISEASE ASSOCIATION

15 Recreation Rd.  
Guilford GU1 1HE

NATIONAL SOCIETY FOR PHENYLKETONURIA (UK) LTD.

7 Lingey Lane  
Wardley  
Gateshead NE10 8BR  
[nspku@ukonline.co.uk](mailto:nspku@ukonline.co.uk)

PHAB England

Summit House  
Waudle Rd  
Croydon CRO 1DF  
(Joint Action for Physical Handicapped)

NATIONAL PHOBICS SOCIETY

Zion CHRC  
Royce Road, Hulme  
Manchester M15 5FQ  
Tel: 0161 227 9898  
Fax: 0161 227 9862  
URL [www.phobics-society.org.uk](http://www.phobics-society.org.uk)  
[natphob.soc@good.co.uk](mailto:natphob.soc@good.co.uk)

POLIOMYELITIS

British Polio Fellowship  
The Ground Floor  
Unit A Eagle Office Centre  
The Runway  
Ruislip  
Middlesex HA4 6SE  
Facsimile: 0181 842 0555  
Fax: 020 8842 0555  
[british.polio@diad.pipex.com](mailto:british.polio@diad.pipex.com)

PORENCEPHALY CONTACT GROUP

Mrs. Wildash  
3 St John's Hill  
Ryde  
Isle of Wight PO33 1HN  
Tel: 01983 563595



PRADER-WILLY SYNDROME ASSOCIATION (UK)

Mrs. Rosemary Johnson  
2 Wheatsheaf Close  
Horsell  
Woking  
Surrey GU21 4BP

Administrative

33 Leopold Street,  
Derby DE1 2HF  
TeleFax: 01332 365676  
[roger@pwda-uk.demon.co.uk](mailto:roger@pwda-uk.demon.co.uk)

THE PRE-ECLAMPSIA SOCIETY

PETS

17 South Av.  
Hullbridge  
Hockley SS5 6NG  
Tel: 01702 232533

PREMATURITY AND SICK NEWBORN

BLISS

17-21 Emerald Street  
London WC1N 3QI  
Tel: 0181 995 0257  
Fax: 0181 995 9075

PRIMARY CILIARY DYSKENESIA

Mrs. Mary O'Downell  
PCD Family Support Group  
16 Graham Road  
Mitcham CR4 2HA  
Tel: 0181 646 3770

THE PRIMARY IMMUNODEFICIENCY ASSOCIATION

Alliance House  
12 Caxton Street  
London SW14 0QS  
Tel: 0171 7640  
Fax: 0171 976 7641  
[pimmune@dial.pipex.com](mailto:pimmune@dial.pipex.com)

PROTEUS SYNDROME FAMILY NETWORK

Sandra Rich  
12 Hayling Av.  
Little Paxton  
St. Neots  
Huntingdon PE19 4HQ  
Tel: 01480 354795  
[zoo03268@zoo.co.uk](mailto:zoo03268@zoo.co.uk)

THE PSORIASIS ASSOCIATION

7 Milton Street  
Northampton NN2 7S6  
Tel: 01604 711129  
Fax: 01604 792894

PSORIATIC ARTHROPATHY ALLIANCE  
P.O. Box 111  
St Albans AL2 3JQ  
TeleFax: 01923 672837  
[office@psalliance.org.uk](mailto:office@psalliance.org.uk)

PURNIE & PYRIMIDINE METABOLIC DISEASES  
PUMPA  
Bockmer Hill House, Bockmer  
Marlow SL7 2HL  
Tel: 01491 571058. [direkyardley@compuserve.com](mailto:direkyardley@compuserve.com)

REFLEX ANOXIA SEIZURES - RAS  
P.O.Box 175  
Stratford upon Avon  
Warwickshire CU37 8YD  
TelFax: 01789 450564  
[trudie@stars.org.uk](mailto:trudie@stars.org.uk)

REFLEX SYMPATHETIC DYSTROPHY SYNDROME SUPPORT GROUP  
'The Shieling' Wester Rd.  
Mailsham BN27 3DY  
Tel: 01323 845313

RESTRICTED GROWTH ASSOCIATION  
P.O. Box 8 Countesthorpe  
Leicester LE8 5ZS  
TeleFax: 0116 2478 913

BRITISH RETINITIS PIGMENTOSA SOCIETY  
P.O. Box 350  
Buckingham MK18 5EL  
Tel: 01280 860363  
Fax: 01280 860515

RETINOBLASTOMA SOCIETY  
c/o Academic Department of Paediatric Oncology  
St Bartholomew's Hospital  
West Smithfield  
London EC1A 7BE  
Tel: 0171 600 3309  
Fax: 0171 60 8579  
[rbinfo@rbsociety.org.uk](mailto:rbinfo@rbsociety.org.uk)

RETT SYNDROME  
Rett Syndrome Association UK  
113 Friern Barnet Rd.  
London N11 3EU  
Tel: 0181 361 5161  
Fax: 0181 368 6123  
[rettassoc@aol.com](mailto:rettassoc@aol.com)

Mrs. Isabell Allan  
National Rett Syndrome Association  
15 Tanzicknowe Drive  
Cambunslang  
Glasgow G72 8RG  
Tel: 041 647662

National Reye's Syndrome Foundation of the UK  
Mrs. Gilliam Denney  
15 Nicholas Gardens  
Pyrford Woking  
Surrey GU22 8SD  
Tel: 01932 346843

RUBINSTEIN TAYBI SYNDROME SUPPORT GROUP  
Rosamary Robertson  
Appledore Cottage  
Dilwyn  
Hereford HR4 8EU

Amanda Clipston  
127 The Drive  
Northampton NN1 4SW  
Tel: 01604 711080. (7/2)

SACRAL AGENESIS  
Mrs. Helen Gillard  
15 Elizabeth Gardens  
Dibden Purlieu  
Southampton  
Hamshire S04 5NP  
Tel: 0703 842661

NATIONAL SCHIZOPHRENIA FELLOWSHIP  
28 Castle Street  
Kingston upon Thames KT1 1SS  
[www.nst.org.uk](http://www.nst.org.uk)  
[info@membership.nsf.org.uk](mailto:info@membership.nsf.org.uk)  
[www.nsf.org.uk](http://www.nsf.org.uk)

SCLERODERMA  
The Raynaud's & Scleroderma Association  
112 Crewe Rd.  
Alsager  
Stoke-on-Trent ST7 2JA  
Tel: 01270 872776

SCOLIOSIS ASSOCIATION (UK)  
Mrs. Pauline Grey  
2 Ivebury Court  
323-327 Latimer Rd.  
London W10 6RA  
Tel: 0181 964 5343

SHWACHMAN SYNDROME SUPPORT NETWORK  
23 Sutherland Grove  
Perton Wolverhampton WV6 7PA  
Tel: 0192 745545 (ev)

SICKLE CELL ANAEMIA  
The Sca Society  
54 Station Rd.  
London NW10 4UA  
Tel: 0181 961 7795  
Fax: 0181 961 8346

SILVER-RUSSELL SYNDROME SUPPORT GROUP  
c/o Child Drowth Families  
Fax: 0181 995 9075

SMITH-MAGENIS FOUNDATION  
P.O. Box 18802  
London SW7 3ZQ  
TeleFax: 0171 373 6562

SPEECH AND LANGUAGE IMPAIRMENT  
AFASIC  
347 Central Markets  
Smithfield  
London EC1A 9NH

AFASIC  
69-85 Old Street  
London EC1V 9HV  
Tel: 020 7841 8900  
Fax: 020 7841 8901  
[www.afasic.org.uk](http://www.afasic.org.uk)  
[info@afasic.org.uk](mailto:info@afasic.org.uk)

ICAN  
4 Dy'ers Buildings, Holborn  
London EC1N 2QP  
[ican@ican.btinternet.com](mailto:ican@ican.btinternet.com)

SOTOS SYNDROME  
Fax: 0181 995 9075

SPINAL INJURIES ASSOCIATION  
76 St James's Lane  
London N10 3DF

SPINAL MUSCULAR ATROPHY  
Jennifer Trust for Spinal Muscular Atrophy  
29b avon House  
New Broad Street  
Straford-upon-Avon  
CV37 6HW  
Tel: 01789 267520  
Fax: 01789 268371  
[jennifer@jtsma.demon.co.uk](mailto:jennifer@jtsma.demon.co.uk)

THE BRITISH STAMMERY ASSOCIATION  
15 Old Ford Road  
London E2 9PJ  
Tel: 020 8983 1003 Fax: 020 8983 3591  
[www.stammering.org](http://www.stammering.org)  
[mail@stammering.org](mailto:mail@stammering.org)

STICKLER SYNDROME SUPPORT GROUP  
P.O. Box 371  
Walton on Thames  
KT12 2YS  
Tel: 61932 267635  
[wendy@stickler.org.uk](mailto:wendy@stickler.org.uk)

STILL BIRTHS & NEONATAL DEATHS  
SANDS  
28 Portland Place  
London W1N 4DE  
Tel: 0171 436 7940. Fax: 0171 436 3715

STROKE (CEREBROVASCULAR ACCIDENT)  
Different Strokes  
Sir Walter Scott House  
2 Broadway Market  
London E8 4QJ  
Tel: 0171 249 6645. Fax: 0171 249 6645  
[different@strokes.demon.co.uk](mailto:different@strokes.demon.co.uk)

STURGE-WEBER SYNDROME FOUNDATION (UK)  
Burleigh  
348 Pinhoe Road  
Exeter EX4 8AF  
Tel: 01392 464675

SERINGORMYELIA  
Mrs. Sue Adshead  
ANTS  
1 Abbey Drive  
Little Haywood  
Stafford ST18 0QQ  
Tel: 0889 882280

TAR SYNDROME SUPPORT GROUP  
(Evan & Susan Edwards)  
40 Ann Beaumont Way  
Hadleigh  
Suffolk  
Ipswich IP7 6SA  
Tel 01473 824324

TAY SACHS  
CLIMB  
The Quadrangle  
Crew Hall, Weston Road  
Crewe, CW1 6UR  
Tel: 01270 250221

UK THALASSAEMIA SOCIETY  
19 The Broadway, Southgate  
London N14 6PH  
Tel: 0181 882 0011. Fax: 0181 882 8618  
[office@ukts.org.uk](mailto:office@ukts.org.uk)

BRITISH THYROID FOUNDATION  
(PAEDIATRIC CONTACT)  
28 Richmond Place  
Bath BA1 5PZ  
Tel: 01225 421348

**BRITISH TINNITUS ASSOCIATION**

4th Floor, White Building  
Fitjalan Square  
Sheffield S1 2AZ  
Tel: 0114 279 6600  
Fax: 0114 279 6222

**TOURETTE SYNDROME (UK) ASSOCIATION**

First Floor Offices, Old Bank Chambers  
London Road, Crowborough, East Sussex TN6 2TT  
Helpline: 01892 669151  
Fax: 01892 663649  
[TSA-UK@compuserve.com](mailto:TSA-UK@compuserve.com) [tsaheadquarters@cs.com](mailto:tsaheadquarters@cs.com)

**TOXOCORIASIS**

Community Hygiene Concern  
Hospital for Tropical Diseases  
4 St Pancras Way  
London NW1 0PE  
Fax: 0181 292 7208

**THE TOXOPLASMOSIS TRUST**

Room 26  
61/71 Collier Street  
London N1 9BE  
Tel: 0207 5931 150

**TOMMY'S CAMPAIGN**

1 Kennington Road  
London  
SE1 7RR  
Tel: 020 7620 0188  
Fax: 020 7928 6628  
[www.tommys-campaign.org](http://www.tommys-campaign.org)  
[mailbox@tommys-campaign.org](mailto:mailbox@tommys-campaign.org)

**TRACHEO-OESOPHAGEAL FISTULA**

Christine Shepherd/Sue Dobbs  
TOFS  
St George's Centre  
91 Victoria Road  
Nethersfield Nottingham NG4 2NN  
TeleFax: 0115 940 0694

**TRACHEOSTOMY**

Aid For Children with Tracheostomies (ACT)  
9 Elmdale Crescent  
North Field  
Birmingham B31 1SL  
Tel: 0121 411 1348  
[actuk@aol.com](mailto:actuk@aol.com)

**TREACHER-COLLINS SYNDROME FAMILY SUPPORT GROUP**

114 Vincent Road  
Thorpe Hamlet  
Norwich NR1 4HH  
Tel: 01603 433736  
[neil@tcfsg.demon.co.uk](mailto:neil@tcfsg.demon.co.uk)

**TUBEROUS SCLEROSIS ASSOCIATION**

Little Barnley Farm,  
Casthill  
Bromsgrove  
Worcs B61 0NQ  
Tel: 01527 871898  
Fax: 01527 579452

**TURNER CENTER**

Cytogenetic Laboratory  
Skovagervej 2  
DK-8240 Risskov, Denmark

**TWINS WITH SPECIAL NEEDS/MULTIPLE BIRTHS**

Multiple Births Foundation  
Queen Charlotte & Chelsea Hospital  
Goldbank Road  
London W6 0XG  
Tel: 0181 740 3519  
Facsimil: 0181 740 3041

**TAMBA -SPECIAL NEEDS SUPPORT**

P.O. Box 30. Little Sutton. South Wirral  
Liverpool L66 1TH  
Tel: 0151 348 0020

**UNIQUE RARE CHROMOSOME DISORDERS**

P.O. Box 2189  
Caterham  
Surrey  
CR3 5GN  
TeleFax: 01883 3307 66

**UPPER LIMB ABNORMALITIES**

'Reach' 12 Wilson Way  
Earls Barton  
Northampton NN6 0NZ (arm & hanmd deficiencies)  
Telefax: 01604 8110441  
[reac@reach.org.uk](mailto:reac@reach.org.uk)

**USHER SYNDROME**

Head of Usher Services  
SENSE  
11-13 Clifton Terrace

**VISUAL IMPAIRMENT**

The Partially Sighted Society  
The Sight Centre  
9 Plato Place  
London SW6 4TU  
Tel: 0171 371 0289

**Vision Aid**

Guy Salmon House  
22a Chorley New Road  
Bolton BL1 4AP

Look  
Queen Alexandra College  
49 Court Oak Rd.  
Birmingham B17 9TG

Menshaw's Society for the Blind  
John Derby House  
88-92 Talbot Road  
Old Trafford  
Manchester M16 0GS

THE VITILIGO SOCIETY  
125 Kennington Road  
London SE11 6SF  
Tel: 0171 840 0844  
Fax: 0171 840 0866  
[www.vitiligosociety.org.uk](http://www.vitiligosociety.org.uk)  
[all@vitiligosociety.org.uk](mailto:all@vitiligosociety.org.uk)

WEST SYNDROME  
Mrs. Ellen Samuel  
West Syndrome Support Group  
8 Waddon Clise  
Croydon  
Surrey CR0 4JT

8 Waddon Close,  
Croydon,  
Surrey  
CRO 4JT  
Tel: 0181 680 8449  
<http://www.wssg.org.uk/wssg/>

WILLIAMS SYNDROME FOUNDATION LTD.  
161 High Street  
Tonbridge TN9 1BX  
Tel: 01732 365152  
Fax: 01732 360178  
[john.nelson-wsfoundation@btinternet.com](mailto:john.nelson-wsfoundation@btinternet.com)

WOLF-HIRSCHHORN Syndrome Support Group  
(Mrs Chris Hilder)  
2b Harvesters Close  
Rainham  
Gillingham HE8 8PA  
TeleFax: 01634 264816



## **SPAIN**

### ***NATIONAL SUPPORT RESOURCES***

#### **REAL PATRONATO DE PREVENCIÓN Y DE ATENCIÓN A PERSONAS CON MINUSVALÍA**

Serrano 140  
28006 Madrid  
Tel: 914415500; 5616240  
Fax: 91411 5502-564 6244  
[www.rppam.es](http://www.rppam.es)  
[rp@futurnet.es](mailto:rp@futurnet.es)

#### **FEDERACIÓN DE ENTIDADES COLABORADORAS CON EL MINUSVALIDO FECOM**

Gran Vía de les Corts Catalanes, 562, pral. 2ª.  
08011 Barcelona  
Tel: 934515550  
Fax: 934516904

#### **PLATAFORMA REPRESENTATIVA ESTATAL DE DISCAPACITADOS FÍSICOS PREDIF**

Calle Orense 8, Oficina 1ª  
28020 Madrid  
Tel: 915149404  
Fax: 915149464  
[www.skios.es/plataforma](http://www.skios.es/plataforma)  
[Predif@nad.servicom.es](mailto:Predif@nad.servicom.es)

#### **FEDERACIÓN DE COORDINADORAS Y ASOCIACIONES DE MINUSVALIDOS FÍSICOS DE LAS CC AA DE ESPAÑA COAMIFICOA**

Calle Gas Lebón, 5.  
46023  
Valencia  
Tel: 963306324

#### **CONFEDERACIÓN COORDINADORA ESTATAL DE MINUSVALIDOS FÍSICOS DE ESPAÑA COCEMFE**

Calle Ríos Rosas, 54-A-bajos centro.  
28003 Madrid  
Tel: 915350619  
Fax: 915350286  
Residencia: C/ Eugenio Salazar, 2.  
28002 Madrid  
[www.cocemfe.es](http://www.cocemfe.es)  
[enmarcha@mad.servicom.es](mailto:enmarcha@mad.servicom.es)

#### **CENTRO ESTATAL DE AUTONOMÍA PERSONAL Y AYUDAS TÉCNICAS CEAPAT**

Calle Los Extremeños, 1. C/v Pablo Neruda  
28018 Madrid  
Tel: 917789061  
Fax: 917784117

Estambrera, 40-1º-D  
26006 Logroño  
Tel: 41500278; 41448113  
Fax: 41449015

ASOCIACION PARA LAS DEFICIENCIAS QUE AFECTAN AL CRECIMIENTO Y AL DESARROLLO

ADAC

Manuel Villalobos, 41

41009 Sevilla

Tel: 954358786

[www.geocities.com/HotSprings/Villa/4521/index.html](http://www.geocities.com/HotSprings/Villa/4521/index.html)

[m.abascal.000recol.es](mailto:m.abascal.000recol.es)

FEDERACION ESPAÑOLA DE ASOCIACIONES ALCER

Calle Nuestra Sra. De la Luz, 55-1ª

28047 Madrid

Tel-Fax: 914625121

AUTISMO EN ESPAÑA

ASOCIACION DE PADRES Y PROFESIONALES DE AUTISMO

CEPRI

Calle San Antonio M Claret, 282 Esc. A2 &-2

08041 Barcelona

Tel: 3493-4351697

Fax: 34-9-344555335

<http://www.aut.tsai.es/scripts/articulo/smuestra.idc?n=cepri>

[jtamarit@correo.cop.es](mailto:jtamarit@correo.cop.es)

ASOCIACION NUEVO HORIZONTE

Av. Comunidad de Madrid, 43

2830 Los Rozas, Madrid

Tel: 3491 6377455

Fax: 3491 6377762

<http://aut.tsai.es/scripts/articulo/smuestra.idc?n=nuetror>

ASOCIACION PAUTA

Patrocinio Gomez 1 bis

28022 Madrid

Tel: 3491 741290

Fax: 3491 3004788

[Juansacaluga@mad.servicom.es](mailto:Juansacaluga@mad.servicom.es)

FEDERACION ESPAÑOLA DE PADRES DE AUTISTA

FEDERACION ESPAÑOLA DE ASOCIACIONES DE PADRES DE AUTISTA

Navaleno, 9

28033 Madrid

Tel: 917662222, Fax: 917670038

[Apna@medusa.es](mailto:Apna@medusa.es)

AGRUPACION DEPORTIVA AUTISMO Y DEPORTE

Calle Costa Rica, 56

09001 Burgos

Tel: 34 9947460034

ASOCIACION NACIONAL PARA PROBLEMAS DE CRECIMIENTO

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[Ademmadrid@iaid.es](mailto:Ademmadrid@iaid.es)

FEDERACION ECOM  
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Fax: 934516904  
[www.ban.es/tjussana/ecom](http://www.ban.es/tjussana/ecom)  
[fedecom2seher.es](http://fedecom2seher.es)

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[www.vnet.es/estu/estu.htm](http://www.vnet.es/estu/estu.htm)  
[estu@vnet.es](mailto:estu@vnet.es)

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46015 Valencia  
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[www.fibrosis.org](http://www.fibrosis.org)  
[fq@vic.servicom.es](mailto:fq@vic.servicom.es)

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Calle Galileo, 69 – Bajo Dcha.  
28015 Madrid  
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[Famma@mad.servicom.es](mailto:Famma@mad.servicom.es)

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28027  
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Tel: 949177907  
Fax: 948266739

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<http://www.serbal.pntic.mec.es/jpons4/pag1.htm>

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[moebius@digitel.es](mailto:moebius@digitel.es)

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28003 Madrid  
Tel: 915336828  
Fax: 915547569  
[www.irinfo.es/prader-willi/index.htm](http://www.irinfo.es/prader-willi/index.htm)  
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[Rettcat@geocities.com](mailto:Rettcat@geocities.com)

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EDUCACION ESPECIAL  
[Home.coqui.net/jalvarez/educa.htm](http://Home.coqui.net/jalvarez/educa.htm)

NECESIDADES EDUCATIVAS ESPECIALES EN INTERNET  
[www.paidos.rediris.es/needirectorio/](http://www.paidos.rediris.es/needirectorio/)

NECESIDADES EDUCATIVAS ESPECIALES  
[www.iceusc.usc.es/necesidadeeducativasespeciais/default.htm](http://www.iceusc.usc.es/necesidadeeducativasespeciais/default.htm)

ASOCIACION PARA LA PROMOCION DEL MINUSVALIDO  
[www.promi.es](http://www.promi.es)

ASOCIACION SINDROME DE DOWN "LEJEUNE"  
[www2.uca.es/huesped/down/](http://www2.uca.es/huesped/down/)

WEB SOBRE EDUCACION ESPECIAL  
[www.ctv.es/USERS/CARLOSDO/](http://www.ctv.es/USERS/CARLOSDO/)

FORO DE DEBATE SOBRE EDUCACION ESPECIAL Y NECESIDADES EDUCATIVAS ESPECIALES  
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ASOCIACION BURGALESA DE MINUSVALIDOS FISICOS  
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ASOCIACION DE PADRES DE PARALITICOS CEREBRALES –PONTEVEDRA  
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ASOCIACION VALENCIANA DE ESPINA BIFIDA  
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APASCIDE  
[www.arrakis.es/~apascide/index.htm](http://www.arrakis.es/~apascide/index.htm).  
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<http://194.224.11.75/utt/home.htm>

TIFLONET. SERVICIO PARA LOS CIEGOS DE HABLA HISPANA  
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[tiflonet@correo.nu](mailto:tiflonet@correo.nu)

WEB DE RETINOSIS PIGMENTARIA. (Asturias).  
<http://retinosis.org>  
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RPLIST: LISTA DE CORREO SOBRE RETINOSIS PIGMENTARIA.  
[Listserw@MAESLTROM-STJOHNS.EDU](mailto:Listserw@MAESLTROM-STJOHNS.EDU).

IRDATA: (Fábrica y venta de nuevas tecnologías de la información y las comunicaciones orientadas a personas y entidades con necesidades especiales)  
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Tel: 34915330529; 34915358134  
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28028 Madrid

Tel: 913565832,

Fax: 913554336

[www.cnse.es/](http://www.cnse.es/)

[cnse@cnse.es](mailto:cnse@cnse.es)

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28001 Madrid

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Fax: 915765746

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(Bonaventura C.V.)

Calle Portal de La Valdigna, 5-2

46003 Valencia

Tel: 963925948

Fax: 963923126

### ASOCIACION DE DIFUSION DE LA COMUNIDAD SORDA

DIFUSORD

Marquez de Sentemant, 37

08014 Barcelona

Fax: 34934052358

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FIAPAS

Nuñez de Balboa, 3 – 1º interior

28001 Madrid

Tel: 915765149

Fax: 915765746

[www.fiapas.es/](http://www.fiapas.es/)

[fiapas@jet.es](mailto:fiapas@jet.es)

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Calle Costada, 14 bajo D, c/v. C/ Agustín Durán, 39 bajo

28028 Madrid

[jgstorch@der.ucm.es](mailto:jgstorch@der.ucm.es)

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Agrupacion de sordos de zaragoza

Comision de educacion

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50003 Zaragoza

TeleFax: 976200362

[Asz@ctv.es](mailto:Asz@ctv.es)

FUNDACION SIN BARRERAS DE Comunicación

[www.a2000.es/sbc/](http://www.a2000.es/sbc/)

[sbc@a2000.es](mailto:sbc@a2000.es)

FUNDACION CANARIA PARA LA PREVENCION DE LA SORDERA

[www.vanaga.es/fcps/intro.htm](http://www.vanaga.es/fcps/intro.htm)

[barajas@iic.vanaga.es](mailto:barajas@iic.vanaga.es)

UNION DE SORDOS DE GUIPUZCOA

[www.facilnet.es/usg/webs/index.htm](http://www.facilnet.es/usg/webs/index.htm)

[usg@facilnet.es](mailto:usg@facilnet.es)

FUNDACION APANDA. Cartagena

<http://www.fundacionapanda.es/>

FEDERACION DE SORDOS DE LA COMUNIDAD VALENCIANA

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<http://personal.redestb.es/faxpg/>

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LA MALETA –RECURSOS PARA SORDOS

[www.xtec.es/~maguirre/indexcas.htm](http://www.xtec.es/~maguirre/indexcas.htm)

[maguirre@pie.xtec.es](mailto:maguirre@pie.xtec.es)

FEDERACION ANDALUZA DE SORDOS

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Centro de Información y Documentación Universitaria  
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Centro de Atención al estudiante  
Cañada de San Urbano s/n.  
04120 Almería.  
Tel: 950215005  
Fax: 950215280  
[www.ualm.es/Universidad/salumno/cidu/cidu-htm3donde](http://www.ualm.es/Universidad/salumno/cidu/cidu-htm3donde)  
[cidu@ualm.es](mailto:cidu@ualm.es)

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07120 Palma de Mallorca  
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[Dcdffo@ps.uib.es](mailto:Dcdffo@ps.uib.es)

UNIVERSIDAD AUTONOMA DE BARCELONA  
Programa de Integración de los Universitarios con Necesidades Especiales  
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Tel: 935812485  
Fax: 935811612  
[www.uab.es/Serveis/PIUNE](http://www.uab.es/Serveis/PIUNE)  
[oas@cc.uab.es](mailto:oas@cc.uab.es)

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08014  
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Campus de Elviña, s/n.  
15071 A Caruña  
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25003 Lleida  
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Prestación Social Sustitutoria  
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Palacio-Hotel Laredo  
Paseo de la Estación, 10  
28807 Alcalá de Henares  
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Tel: 918802823  
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28903 Madrid.  
Tel: 916249606

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Despacho 1616, Depto de Psicología Social

Facultad de Ciencias Políticas y Sociología

28002 Madrid

Campus de Somosaguas

[Soaulz@sis.ucm.es](mailto:Soaulz@sis.ucm.es)

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PAED

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28040 Madrid

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[www.ocm.es/otros/solidarios/index.html](http://www.ocm.es/otros/solidarios/index.html)

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CIDAD

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Ciudad Universitaria, s/n.

28040 Madrid

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29071 Málaga

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Calle Argüelles, 39 pral.

330033 Oviedo

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Edificio Jurídico Social  
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37005 Salamanca  
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[www.usal.es/inico/inico.html](http://www.usal.es/inico/inico.html)  
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SACU: Area de Asesoramiento Psicológico y Social  
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Avda. de Chile, s/n.  
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[www.acceso.uv.es/Centro](http://www.acceso.uv.es/Centro)  
[celeste.asensi@uv.es](mailto:celeste.asensi@uv.es)

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Centro de Estudios para el Desarrollo de Ayudas Técnicas y Sistemas de Integración Socio-Laboral para Personas Discapacitadas.  
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## **DOWN'S SYNDROME ASSOCIATIONS**

### ***UNITED KINGDOM***

Down's Syndrome Association  
155 Mitcham Road,  
London SW17 9PG  
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Fax: 0181-682-4012  
[www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)  
[info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk)

IRELAND  
DS IRELAND  
May Gannon, 50 Moorfield Park  
Newbridge  
Co -Kildare

SCOTLAND  
THE SCOTTISH DOWN'S SYNDROME ASSOCIATION  
158/160 Balgreen Road  
Edinburgh  
EH11 3AU  
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Fax: 0131 313 4285

DOWN'S SYNDROME WITH HEART DEFECT  
Penny Green  
The Down's Heart Group  
17 Cantilupe Close  
Eaton Bray  
Dunstable LU62EA  
Tel: 01525 220379  
[Downs-Heart-Group@msn.com](mailto:Downs-Heart-Group@msn.com)

The Re-Pete Fund  
7 Rectory Rd.  
London E17 3BG  
or  
41a Thornhill Square  
London N1 1BE  
Tel: 0181 520 3693  
Tel/fax: 0171 700 6189

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South East Thames Branch  
32 Iris Crescent  
Bexley Health, Kent DA7 5QD  
Tel: 02083105018

Tonbridge & District Branch  
60 Tulsham Way  
Paddock Wood, Tonbridge, Kent TN12 6UB  
Tel: 01892 838496

Bexley Branch  
7 Edwin Close  
Bexley, Kent  
DA7 5QH

Lewisham Branch  
33 Colfe Road  
London  
SE23 2ES  
Tel: 02082914372

Tenderden Branch  
Sunningdale  
Further Wquarter Hamstreet  
High Halden Ashford Kent TN26 3HN  
Tel: 01233 850704

Thanet Branch  
26 Thanet Road  
Margate, Kent CT9 1UA  
Tel: 01843 296278

Brighton Branch  
430 Falmer Road  
Woodingdean  
Brighton, East Sussex BN2 6LG  
Tel: 01273 308666

Greenwich Branch  
93 Gerda Road,  
New Eltham  
London SE9 3SH  
Tel: 020 8850 0861

Mid Kent Branch  
51 Cherry Orchard  
Dilton  
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Bromley Branch  
87 Southover  
Bromley  
Kent BR1 4SI  
Tel: 02086956320

Kingston Branch  
22 Heatherdale Crescent  
East Preston  
Littlehampton Sussex BN16 1DS  
Tel: 01903772

Sutton Branch  
29 Camborne Road  
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Woodham Surrey KT15 3QF  
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Tel: 01237 422461

Devon & Cornwall Branch  
Threeways Bungalow, Pyworthy  
Holsworthy Devon EX22 6LQ  
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Yelverton Devon PL20 7PF  
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Birmingham, West Midlands B28 0LE  
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Sandwell Warler/West  
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North Somerset Branch  
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34 John Street, Ballymoney  
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Tel: 02827666394

County Fermanagh Branch  
53 Hillview Park  
Enniskillen BT14 6ET  
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Lisburn, County Antrim BT26 1HB  
Tel 02892679739

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Downpatrick, Northern Ireland BT30 3EQ  
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Tel: 01254393148

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Tel: 01422 369845

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Silsden, Nr. Keighley BD20 9PS  
Tel: 01535653935

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Bradford Branch  
21 Hollingwood Mount  
Bredford, West Yorkshire BD7 4DD  
Tel: 01274 573623

Wakefield & Pontefract Branch  
14 Alexander Crescent  
Featherstone  
Pontefract, W. Yorks WF7 6LG  
Tel: 01977797603

Lincoln Branch  
3 Reynolds Paddock  
Aubourn, Lincoln LN5 5EW  
Tel: 01522 7889135

Isle of Man Branch  
Ghoon Rushen  
Surby Road Ballafesson  
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Central Notts Branch  
11 Dunelm Close  
Sutton-In-Asfield, Notts NG17 2EX  
Tel: 01623 459426



Bassetlaw Branch  
3 Conway Drive  
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19 North Road, West Bridgford  
Nottingham, Nottinghamshire NG2 7NG  
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17 The Grange, Ashgate  
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Rotherham Branch  
5 Gaunt Road  
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31 Blissett Road  
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South Warwickshire Branch  
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DOWN SYNDROME CORPORATION  
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[www.chasque\\_apc.org/nexo/asocdwon/indexdow.htm](http://www.chasque_apc.org/nexo/asocdwon/indexdow.htm)  
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ASOCIACION SINDROME DE DOWN DE EXTREMADURA  
<http://www.downnex.org/>

ASOCIACION SINDROME DE DOWN DE MALAGA  
Calle Godino, 9  
29009 Málaga  
Tel: 95227440  
Fax: 952274050  
[www.activanet.es/ong/down/index-htm/](http://www.activanet.es/ong/down/index-htm/)  
[down@activanet.es](mailto:down@activanet.es)

**ASOCIACION SINDROME DE DOWN LEJEUNE –CADIZ Y BAHIA**

Recinto Interior Zona Franca  
Edif. Altos. Módulos B15-B17  
11011 Cádiz  
<http://www2.uca.es/huesped/down>  
[asociacion.sindromedown@uca.es](mailto:asociacion.sindromedown@uca.es)

**CENTRO DE NIÑOS DOWN  
CEDOWN**

Plaza de Los Angeles, Parcela 9, Local 5  
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CONFEDERACION ESPAÑOLA DE FEDERACIONES Y ASOCIACIONES PRO PERSONAS  
DEFICIENTES MENTALES  
(Dr. Miguel Angel Verdugo)  
Calle General Perón ,32 1º  
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[www.sindromedown.net](http://www.sindromedown.net)  
[feisd@sindromedown.net](mailto:feisd@sindromedown.net)

**FUNDACIO CATALANA SINDROME DE DOWN**

Calle Valencia, 229  
08007 Barcelona  
Tel: 932157423  
Fax: 932157699  
[www.fcd.org/index\\_cs.htm](http://www.fcd.org/index_cs.htm)  
[integra@fcsd.org](mailto:integra@fcsd.org)

**FUNDACION ASINDOWN**

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46014 Valencia  
Tel: 963834298; 963833153  
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[www.valencianet.com/ongs/asindown.htm](http://www.valencianet.com/ongs/asindown.htm)  
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Russian Federation

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National DS Society -  
NDSS: Education, Research, Advocacy  
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New York, NY 10012-2317  
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Fax: 212-979-2873  
[www.ndss.org](http://www.ndss.org)  
[info@ndss.org](mailto:info@ndss.org)  
(Robert Bonney; Program Manager;  
(Education, Research, Advocacy).

National Mosaic Down Syndrome Association  
P.O.Box 77272  
West Trenton, NJ 08628-6272  
Voice/Fax 609-806-6372 (MDSA)  
[www.mosaicdownsyndrome.com](http://www.mosaicdownsyndrome.com)  
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Department of Human Genetics  
Virginia Commonwealth University  
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(Dr. Jackson-Cook has an ongoing research project on mosaic Down syndrome.

Richard Koch, M.D.  
Clinical Pediatrics  
University of Southern California,  
School of Medicine  
4650 Sunset Blvd. Los Angeles, CA 9007  
Tel: 213-669-2152  
(Dr. Koch has conducted research and published his findings on mosaic Down Syndrome).

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Reseda Blvd # 109  
Northridge, CA 91324-3943  
USA  
Tel: 818 718 6363  
818 718 8949

Down Syndrome Association of Greater Cincinnati (DSAGC)  
1821 Summit Road, Suite G-20  
Cincinnati, OH 45237  
Tel: 513-761-5400

Ventura County Down's Syndrome Association  
P.O. Box 6850  
Oxnard, CA 93031  
Tel: 805-378-5129

Down Syndrome Association of San Diego  
P.O. Box 881883  
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Puerto Rico Down Syndrome Foundation  
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Associazione Nazionale Persone Down  
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Tel: 06/3723909.  
Fax: 06/3722510  
(Federica Girard)

Sindrome Down Notizie:  
<http://www.aipd.it>  
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Tel: 0825/622708

Alta Gallura

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Tempio Pausania (SS)

TeleFax: 079/631261

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Via M. Galliani, 7/C,

70125 Bari

Tel: 080/5564368.

Fax: 080/5429926

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32034 Pedavena (Belluno)

Tel: 0439/300953

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c/o Maria Eleonora Piciocco

Piazza Cairoli, 28

72100 Brindisi

Tel: 083/523844

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86100 Campobasso

Tel: 0874/62686

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81100 Caserta

Tel: 0823/442132

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95125 Catania

Tel: 095/414191

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Viale della Repubblica, 335

87100 Cosenza

Tel: 0984/793893

Matera

Sig.ra Barile- Viale dei Bruzi, 7

75100 Matera

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Via S. Caterina, 38

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Tel: 0382/454275

Perugia  
Sig. Valloni - Via del Vivaio, 19  
06079 S. Marino in Campo  
Tel: 075/6099317

Piacenza  
Sig. Mauro Chiodarolio  
Via Castello, 29  
29100  
Piacenza  
Tel: 0523/307432

Pisa  
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56100  
Pisa  
Telefax: 050/48689

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Sud-Pontinio  
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Taranto  
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Castello 2785 - 30122  
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Via C. Cattaneo, 54/C  
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European Down Syndrome Association  
Rue Victor Close 41  
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Belgium  
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(Richard Bonjean/ Secret. General)

## **Attention Disorders and Hyperactivity**

The Attention Deficit Information Network, (AD-IN)  
475 Hilside Ave, Needham, MA 02194  
671-455 9895  
(A non profit volunteer organization offering support and information to families of children with ADD, adults with ADD and professionals).

Children and Adults with Attention Deficit Disorders (CHADD)  
499 Northwest 70 th Ave, Suite 101  
Plantation, FL 33317  
1-800 233 4050  
<http://222.chadd.org/>

National Attention Deficit Disorder Association  
P.O. Box 488  
West Newbury, MA  
1-800 487 2282  
(A parent support association).



## **EUROPEAN UNIVERSITIES WITH SUPPORT SERVICES**

### **UNIVERSITY JOHANNES KEPLER -LINZ –AUSTRIA**

Computer Science for the Blind  
Department for Computer Science  
Altenbergerstrasse 69  
4040 LINZ  
[www.mvblind.uni-linz.ac.at](http://www.mvblind.uni-linz.ac.at)  
[klaus@mvblind.uni-linz.ac.at](mailto:klaus@mvblind.uni-linz.ac.at)

### **UNIVERSITE CATHOLIQUE DE LOUVAIN- BELGIUM**

Association des Services d'Aide  
Rue des Wallons 10.  
B. 1348 Louvain-La-Neuve  
Tel: 10463394  
[Ledent@asal.ucl.ac.be](mailto:Ledent@asal.ucl.ac.be)

### **UNIVERSITE CLAUDE BERNARD -FRANCE**

Lyon 1, Bat. 305  
43 Bd du 11 Novembre 1918  
69622 Villeurbanne Cedex  
Tel: 3372448279  
[Deberti@chitheol.univ-lyon1.fr](mailto:Deberti@chitheol.univ-lyon1.fr)

### **UNIVERSITY OF KARLSRUHE –GERMANY**

Studienzentrum für Sehgeschädigte  
Engessesrt, 4.  
D-76128 Karlsruhe  
Tel: 497216082760

## **MISCELLANEOUS**

### ***SPEECH AND LANGUAGE IMPAIRMENTS***

#### **AFASIC**

69 Old Street  
London EC1V 9HX  
Tel: 0207 841 8900  
Fax: 0207 841 8901

#### **ASSOCIATION OF SPEECH & LANGUAGE THERAPISTS IN INDEPENDENT PRACTICE**

Tel: 01630 655 858  
[asltipuk@aol.com](mailto:asltipuk@aol.com)

#### **DYSLEXIA**

The British Dyslexia Association  
98 London Road  
Reading  
Berkshire RG1 5AU  
Tel: 0118 966 2677  
Fax: 0118 935 1927  
[www.bda.-dyslexia.org.uk](http://www.bda.-dyslexia.org.uk)  
[info@dyslexiahelp-bda.demon.co.uk](mailto:info@dyslexiahelp-bda.demon.co.uk)

The Dyslexia Institute  
133 Gresham Road  
Staines TW18 2AJ  
Tel: 01784 463851  
Fax: 01784 460747

DYSPRAXIA  
The Dyspraxia Foundation  
8 West Alley  
Hitchin SG5 1EG  
Tel: 01462 454986

HEALTHCALL DISCOVERY CENTRE  
For Dyspraxia, Dyslexia and Associated Learning Difficulties  
12 Cathedral Road  
Cardiff CF1 9LJ  
Tel: 01222 222 011

MAKATON VOCABULARY DEVELOPMENT PROJECT  
31 Firwood Drive  
Camberley  
Surrey GU15 3QD  
Tel-Fax: 01276 61390

PAGET GORMAN SOCIETY  
2 Dowlands Bungalows  
Dowlands Lane  
Smallfield  
Surrey RH6 9SD  
Tel: 01342 842 308  
[www.pgss.org](http://www.pgss.org)

ROYAL COLLEGE OF SPEECH & LANGUAGE THERAPISTS  
2 White Hart Yard  
London SE1 1NX  
Tel: 0207 378 3012/3

STASS  
North Road  
Ponteland  
Northumberland NE20 9UR  
Tel: 01661 822 316  
Fax: 01661 860 440

## **SOME U.S.AMERICAN ASSOCIATIONS, SERVICES ON DISABILITY AND SPECIAL EDUCATION**

NATIONAL INFORMATION CENTER ON CHILDREN AND YOUTH WITH DISABILITIES  
(NICHCY) P.O.Box 1492  
Washington, DC 20023-1492  
Tel: 800-695-0285  
<http://www.nichcy.org>  
(Provides free information on disabilities and disability-related issues).

ACCESS TO RESPITE CARE AND HELP (ARCH)  
The Chapel Hill Training-Outreach Project  
800 Eastowne Drive  
Chapel Hill, NC 27514  
Tel: 800-473-1727 or 800-773-5433  
(It maintains a database of organizations that provide respite services throughout the USA).

AMERICAN ASSOCIATION OF UNIVERSITIES AFFILIATED PROGRAMS (AAUAP)  
8630 Fenton Street, Suite 410  
Silver Spring, MD 20910  
Tel: 301-588-8252  
(It supports the independence, productivity, integration and inclusion of individual with developmental disabilities into the community).

CENTER OF HUMAN POLICY  
Syracuse University, 200 Huntington Hall  
Syracuse, NY 13244-2340  
Tel: 513-443-3851  
(Research, policy and advocacy organization involved in the national movement to ensure the rights of people with disabilities).

COOKE CENTER FOR LEARNING & DEVELOPMENT  
475 Riverside Drive, Suite 730  
New York, NY 10115  
Tel: 212-280-4473  
(It is dedicated to advocating and providing inclusive education placements for children with disabilities in New York City).

CHROMOSOME DELETION OUTREACH, INC.  
P.O.Box 724 Boca Raton, FL 33429-0724

DISABLED AND ALONE; LIFE SERVICES FOR THE HANDICAPPED, INC.  
352 Park Avenue South, Suite 703  
New York, NY 10010-1709  
Tel 800-995-0066 or 212-532-6740

ESTATE PLANNING FOR PERSONS WITH DISABILITIES  
1200 Corporate Drive, Suite 330  
Birmingham, AL 35242  
Tel: 205-803-6800  
(For educational seminars).

EXPECTATIONS UNLIMITED, INC.  
P.O.Box 655  
Niwot, CO 80544  
Tel: 303-652-2727  
(It distributes video presentations and conference recordings on inclusive education).

**FEDERATION FOR CHILDREN WITH SPECIAL NEEDS**

95 Berkeley Street, Suite 104

Boston, MA 02116

Tel: 617-482-2915

(To make parents aware of their legal rights under P.L. 94-142 and to provide information, advocacy and training).

**INCLUSION PRESS/CENTRE FOR INTEGRATED EDUCATION AND COMMUNITY**

24 Thome Crescent

Toronto, Ontario M6H 2S5

Canada

Tel: 416-658-5363

Fax: 416-658-5067

(It provides books, videos and printed matter regarding inclusion).

**INSTITUTE ON COMMUNITY INTEGRATION**

University of Minnesota

150 Pillsbury Drive, S.E.

Minneapolis, MN 55455

Tel: 612-624-4512; 612-624-6300

(It facilitates the independence of citizens with disabilities and their social integration into community life. It conducts more than 60 projects).

**NATIONAL CENTER ON EDUCATIONAL RESTRUCTURING AND INCLUSION (NCERI)**

The Graduate School and University Center,

The City University of New York

33 West 42 Street New York, NY 10036

Tel: 212-642-2656

(It promotes educational programmes in inclusive settings).

**NATIONAL FAMILY CAREGIVERS ASSOCIATION**

9621 East Bexhill Drive

Kensington, MD 20895-3104

Tel: 301-942-6430

**NATIONAL INSTITUTE ON LIFE PLANNING FOR PERSONS WITH DISABILITIES, INC.**

CIHS-Sonoma State University

1801 F. Cotati Avenue

Rohnert Park, CA 94928

Tel: 707-664-4235

**NATIONAL PARENT NETWORK ON DISABILITIES**

1130 - 17th Street, NW, Suite 400

Washington, DC 20036

Tel: 202-463-2299

(It sponsors the inclusion training projects).

**PARENTS ADVOCACY COALITION FOR EDUCATIONAL RIGHTS (PACER) CENTER**

4826 Chicago Avenue South

Minneapolis, MN 55417-1098

Tel 612-827-2966

(It conducts workshops, training and disseminates information on disabilities).

**PARENTS EDUCATION AND ASSISTANCE FOR KIDS (PEAK) PARENT CENTER, INC.**

6055 Lehman Drive, Suite 101

Colorado Springs, CO 80916

Tel: 719-531-9400

(It develops informational materials, curricula, training guides and a newsletter).

**SCHOOLS ARE FOR EVERYONE (SAFE)**

P.O. Box 9503

Schenectady, NY 12309

(It supports the placement of children in inclusive settings).

**SPECIAL EDUCATION RESOURCE CENTER (SERC)**

25 Industrial Park Road

Middleton, CT 06457

Tel: 203-632-1485

(It provides bibliographies and resource lists regarding inclusion).

**Woodbine House**

Special-Needs Collection Catalog

6510 Bells Mill Road, Bethesda, MD 20817

Tel: 800-843-7323

**THE ASSOCIATION FOR PERSONS WITH SEVERE HANDICAPS (TASH)**

11201 Greenwood Avenue North

Seattle, WA 98113

Tel: 800-482-TASH (8274).

**THE FAMILY CONNECTION, BEACH CENTER ON FAMILIES AND DISABILITY**

3111 Haworth Hall - University of Kansas

Lawrence, KS 66045 -Tel: 800-854-4938-

(It conducts research on the causes of challenging behavior and strategies)

**THE MARCH OF DIMES BIRTH DEFECTS FOUNDATION**

1275 Mamronck Ave.

White Plains, New York 10605

888-MODIMES(663-4637)

**THE NATIONAL TAY-SACHS & ALLIED DISEASE ASSOCIATION**

2001 Beacon St.,

Brookline, MA 02146

Tel: 617 277 4463

[Resourcecenter@modimes.org](mailto:Resourcecenter@modimes.org)

**ADHA**

The Attention Deficit Information Network, (AD-IN)

475 Hilside Ave, Needham, MA 02194

671-455 9895

(A non profit volunteer organization offering support and information to families of children with ADD, adults with ADD and professionals).

**Children and Adults with Attention Deficit Disorders (CHADD)**

499 Northwest 70 th Ave, Suite 101

Plantation, FL 33317

1-800 233 4050

<http://222.chadd.org/>

**National Attention Deficit Disorder Association**

P.O. Box 488

West Newbury, MA

1-800 487 2282

(A parent support association).

## TECHNOLOGY SUPPLIERS

The Alliance for Technology Access  
2173 East Francisco Blvd., Suite L.  
San Rafael, CA 94901  
Tel: 415-455-4575

(National network of centers that can assist in choosing hardware and software).

The RESNA Technical Assistance Project  
1700 N. Moore Street, Suite 1540  
Arlington, VA 22209  
Tel: 703-524-6686

Apple Worldwide Disability Solutions Group  
Apple Computer, Inc.  
20525 Mariani Avenue  
Cupertino, CA 95014  
Tel: 800-600-7808

IBM Independence Series Information Center  
P.O. Box 1328  
Boca Raton, FL 33429-1328  
Tel: 800-426-4832

Funding  
Assistive Technology Funding and Systems Change Project  
1660 L Street NW, Suite 700  
Washington, DC 20036-5602

## **INTERNATIONAL AGENCIES AND ASSOCIATIONS**

Disabled Persons Unit  
Department for Policy Co-ordination  
United Nations, Room DC2- 1302  
New York, NY 10017 USA

American Association on Mental Retardation  
AAMR, 444 North Capitol Street  
NW Suite 846, Washington,  
D.C. 20001 - 1512, USA  
Tel: 1(202) 387 - 1968 or (800) 424-3688  
Fax: 1(202) 387 2193  
[www.aamr.org/](http://www.aamr.org/)  
[info@aamr.org](mailto:info@aamr.org).

Asociación Mundial de Educación Especial  
c/ Micenas 143. Urbanización Monte Rozos  
28230 Los Rozos  
Madrid  
Tel/fax: 3491 631 6564  
Orlando Terré  
[Garabato.terre@ncsa.es](mailto:Garabato.terre@ncsa.es)

INCLUSION PRESS  
24 Thome Crescent, Toronto, ON  
Canada M6H 2S5  
Tel: 416 658 5363  
Fax: 416 658 5067  
[www.inclusion.com](http://www.inclusion.com)  
[74640.1124@compuserve.com](mailto:74640.1124@compuserve.com)  
[includer@idirect.com](mailto:includer@idirect.com)





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